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**Broken Hearts and the Heart Broken: Living With, and Dying From,
Heart Failure in Scotland**

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Statement of Originality

All the work recorded in this thesis is original unless otherwise acknowledged in the text or by references. None of the work has been submitted for another degree in this or any other University.

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Abstract

Heart failure is a common and serious chronic condition, which can be as 'malignant' as most forms of cancer (Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001). Recent estimates are that around 40,000 men and 45,000 women are living with heart failure in Scotland (Stewart, MacIntyre, Capewell, & McMurray, 2003). Heart failure is significantly influenced by socioeconomic factors, with people on lower incomes being more likely to develop, and die faster from, heart failure (McAlister et al, 2004). There is a growing body of research on the experience of living with heart failure, however, none provides serious consideration of the role of socioeconomic factors in impacting the experience of heart failure, and some qualitative research may actually obscure such factors. There were two main aims in this thesis. One was to explore how qualitative research methods can better consider the relationship between experience and broader context, such as the influence of socio-economic factors on health. The other aim was to examine the experiences of people as they live with and die from heart failure in ways that situate their accounts in the broader context of their lives.

An initial research study, on which I was the main researcher, focused on the experiences of 30 people living with advanced heart failure. These people, their carers and key health professionals were interviewed, where possible, three times over a six months period. This thesis re-examines that study, focusing on 20 of those participants, for which a total of 122 interviews were conducted. I used a dialogical approach to see whether the socioeconomic context of heart failure for these respondents, could be captured through exploring experiences, performance, relationships, discourses and institutional practices, the social processes that mediate the relationship between socioeconomic disadvantage and chronic diseases were explored. This offers important learning in relation to the experience of living with heart failure, along with the experience of providing care. The findings highlight the need to broaden our view of chronic illness beyond biomedical approaches, and grow our methodological approaches along with that, in order to develop knowledge and practice that has relevance for people who live with and die from heart failure.

For Jack, the tiniest broken heart of all.

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1 Introduction

And if there's one thing, if I ever take that again, and I'm right out, I don't want to come back. (Linda)

These were Linda's words to me as I visited her at a day hospital in Edinburgh, as she described her wish to not be revived should she become unconscious again, due to her heart problems. I met Linda as I went to meet and talk with people who were living with end stage heart failure. The experience of living with and dying from heart failure is the focus of this thesis. By focus I mean that I aimed to learn more about what it is like for people to live with and die from heart failure, but equally, this thesis led me to explore how qualitative methods contribute to knowledge about people's experience. In particular, this thesis aimed to open lines of inquiry into the ways in which qualitative methods understand experience in the context of people's lives, including their socioeconomic circumstances. In particular I will explore how the perspective of structural violence (Farmer, 1999, 2004) may help situate experience in a broader context.

This thesis focused on the experiences of 20 people living with advanced heart failure, and as such was interested in the care people received, including palliative care. Participants, their carers and key health professionals were interviewed, where possible, three times over six months (at initial contact, around 6 weeks later, and then approximately four to five months later). Six participants died during the study. I conducted 48 interviews with people with heart failure, 38 interviews with their nominated carers and an additional 36 interviews with professionals. The professionals interviewed included heart failure nurses, GP's, Geriatricians, nurses, hospice nurses, a volunteer and a district nurse. Overall I conducted and analysed a total of 122 interviews for this thesis. This represents a subset of data from a larger study of 30 participants. That study was funded by the British Heart Foundation and the Department of Health, and was called *Patients', carers' and professionals' experiences of diagnosis, treatment and end-of-life care in heart failure: A prospective qualitative interview study*. Here however, I focus on 20 participants, as they represent those I exclusively did the fieldwork for. This thesis is an extension of the work conducted for the larger funded study, taking the analysis further along lines of enquiry that were generated by my participation in, and the analysis I conducted for, the original study.

I open this thesis with a detailed account of my experience of meeting and interviewing Linda (pseudonyms are used for all participants throughout this thesis). This is for a number of reasons, all of which are central to the arguments that develop through this thesis. The first is that experience is central to qualitative analysis, and I will draw on perspectives that highlight the importance of the role of the researcher in making sense of those experiences. As such, the following account of Linda's story is as much about me, as it is about Linda. By sharing this formative experience, I hope to be transparent about what has influenced my approach and analysis to this work.

The second reason for describing my experience of Linda, is that throughout this thesis I struggled to write about the care people with heart failure received without expressing judgment of the professionals who deliver it. Nurses and doctors withheld diagnoses and prognosis, medicalised patients, avoided talking about dying, tried to enforce self-management, withheld services and imposed their medical world view on the explanations of causes of heart failure. I had found it straightforward to attribute such actions to individual practitioners, to even lay blame for practice that seemed problematic, with those individuals. In some ways this amounted to making an over-emphasis of the role of agency, without considering other more structural influences on people. Yet, as a researcher, and particularly in relation to Linda, I learned that I was also capable of making such mistakes, and indeed over-estimating my own sense of agency as a researcher. Whilst it was humbling to realise my own potential for the sorts of practices I had judged others for, it was also an opportunity to think about how broader processes can influence and shape behaviour, beyond our intentions. What I learnt in my contact with Linda is that I could make those mistakes too, despite my intentions. I, just like the people and the professionals in this story, am part of a complex series of relationships, discourses and social contexts that influence how I think and act. This was influential to my thinking about professional practice as it pertains to heart failure.

As a consequence, much of this thesis advocates for methods that avoid the pitfalls of qualitative work that disconnects individuals from their context. This lack of context can lead to methods that may obscure such things as socioeconomic environments, from the way people describe their experience. Even as I try to explore methods that avoid such individualising, it is a constant challenge to achieve this. The ways in which experiences are analysed, described, summarised and represented constantly challenge the idea of retaining context. Reflecting on how I made sense of Linda's story, the context of her

experience, and my own participation in it, was central to how this thesis developed. By sharing my detailed experience of Linda, I aim to lay a foundation for this thesis, both of my own sense-making and of Linda's experience.

1.1 Linda's Story

Linda was a research participant who particularly stuck in my mind throughout the research conducted for this thesis. I learned through my contact with Linda, the importance of remembering that I was not immune to making mistakes and misjudgements as a researcher.

The first time I met Linda was at a local day hospital, where staff had been supportive of helping to find people to participate in this research. Linda was 80 years old, and most of the people at the day hospital were elderly. I arrived there and asked if someone could introduce me to Linda. The day hospital had a communal area where patients sat on high backed chairs. Some sat alone; others sat chatting to those beside them. Cups of tea, lunch and a range of inputs from medical professionals were provided (from monitoring symptoms to physiotherapy). Linda sat alone, finding it hard at times to stay awake. I sat beside her and explained that I was a researcher who was interested in learning more about what it was like to be living with heart trouble. Linda seemed pleased to agree to have a chat with me, and we went to a quiet clinical side room with a cup of tea. Linda was mobile with the help of a walking frame, but frail, so we walked slowly away from the communal area of the day hospital and to the private room.

As part of the study protocol approved by the local ethics committee, I had an ethical obligation to never mention the words heart failure, unless the patient did so first (so to prevent accidental disclosure of a diagnosis of heart failure). Such a protocol was standard practice when working with health conditions where it could be unclear if a diagnosis had been shared with a patient or not. I had mixed feelings about not talking directly about what my research topic was and didn't like needing to use euphemisms. I quickly discovered that Linda didn't know her diagnosis and we never talked about 'heart failure', but about her health, life, wellbeing and heart troubles. I felt reassured it was right for me not to mention 'heart failure' as I did not have the knowledge, expertise or appropriate role for initiating such a discussion, but I also understood that this meant that informed consent

in this study would also be a compromised process as I might not always be able to clearly explain my purpose.

As we talked, Linda described herself as feeling down, unwell and unable to cope on her own. In contrast she also described the good old days to me, when she was much younger and worked for a lemonade factory. She loved both the work and her independence at that time. She described how she now felt she was like a big baby, and hated having to rely on other people for help. She talked about how her sister had died about a year ago, and how she missed her terribly. She confided how she felt she would not want to be resuscitated should she become unwell again although she hadn't shared that wish with any of the professionals involved in her care. Linda talked about how she would shut her eyes to it all and try to sleep her way through her periods of despair and frustration. She described herself as lost, and she seemed lost to me too.

I hadn't fully appreciated how serious the impact of heart failure might be on daily life before meeting Linda. Linda was facing huge struggles in staying mobile and staying awake. The constant breathlessness left her body oxygen starved and incredibly tired. She had lost her feelings of strength and independence. Despite this, she talked about her dream to visit Australia one day with her closest friend, a former neighbour that she now considered to be like a daughter. Most of Linda's days were days of poor health, but some were certainly much worse than others and the sense of imminent, acute and unpredictable declines in her health, hung over her.

Linda knew she had some heart difficulties, but didn't know what was wrong with her heart. She knew she'd had a heart attack and was now on some heart related medication. She did know that her heart problems were responsible for the intense drowsiness she would experience, and she would drift in and out during our interview. When I asked her if she would like to know more about her heart she answered 'I dare say'. Her consultant had not told Linda much about what was wrong with her heart, feeling that it wasn't right to tell her that she had a poor prognosis whilst she was feeling so low. Linda didn't know she had heart failure or that it was serious enough for her to be considered a participant for this palliative care research project. I asked Linda if she would be happy for us to meet again in a month or two, so I could see how she was getting on, and she agreed to further contact.

When it came time for us to do our second interview together six weeks later, Linda was no longer attending the day hospital. Linda had agreed I could have her home contact details, but I was not able to locate her at home. Linda didn't have any family I could speak with (her only relative was one quite distant nephew), and the person she had nominated as her carer I could contact, her old neighbour, didn't return my calls. I knew this meant there was a strong possibility that she might have been readmitted with a new acute difficulty, but what I hadn't anticipated was the number of potential places she could have found herself admitted to. Eventually I found Linda, but it took phone calls to two different hospitals, conversations with medical records departments and contact with a number of different wards before I located her on a renal ward at a different local hospital. I was surprised at how easily Linda could slip in and out of the various systems of care that respond to the needs of people living with heart failure, and how easily I had managed to lose someone who already felt a little lost in other ways too, in those systems that were charged with caring for her.

I had learnt a lot from the challenges Linda faced in her daily life and how the fragility of her health could lead her on a journey around a number of health systems. At our first meeting she was in the process of making the transition back to her home, following a period of being an inpatient at a geriatric hospital. Quick and unexpected turns of events characterize heart failure, and deterioration in her health had led her to develop renal failure and she moved through different parts of the hospital system in ways that made it hard for me to follow her. Linda, without family members to direct me to her, became submerged into places that were hard to find and, for me, unexpected. It was the first time I had nearly lost a research participant, and I was relieved when I finally found her. I prepared to go and visit her on the ward for our second interview and was curious to learn more about the turn of events that had led her back to hospital.

1.1.1 The Disintegrated Diagnoses of Linda

Linda had seemed so unwell to me when I first met her that I felt it was likely I would not see her again, and even though medical professionals had described life with heart failure as being characterised by ups and downs, it was quite surprising to see the rise and fall in her health. Eventually when I found Linda on a renal ward, she had been there for 12 weeks. I learned that during this time she was bed bound, unable to watch the television or even talk on the phone, as she couldn't hear either, and neither the phone or television seemed to work with her hearing aid. For much of this time Linda was in the bed located by a wall, without a window to look out of. She had been reviewed by a psychiatrist after staff noticed her mood was low. I knew from our previous discussion that she wouldn't be pleased to have been in hospital again, and I decided to bring her in some lemonade to remind her how I had enjoyed hearing about that earlier part of her life when she enjoyed working in the lemonade factory.

When I arrived, I found Linda had been moved to what had often been described to me by other participants as the widely feared single occupancy side room, the place you find might yourself when you are seriously unwell or preparing to die. Linda was very frail, disorientated and sleepy. She had very low blood pressure and was on constant oxygen. I sat with Linda at her bedside. At first she was a little unsure of who I was, and it took a little time to explain why I was there and how we had met before. She seemed to need some comfort and reassurance, and I held her hand as we talked quietly together. She told me how she wanted to be buried with her childhood doll and her wish for a particular passage from the Bible to be read at her funeral. Linda talked about her childhood memories of holidays in Blackpool with her sister and how these memories would pass through her mind, alongside feelings of being confused about time. She felt she would soon 'meet her maker' and described how dying preoccupied her thoughts at night. I sat there not to interview her, but to keep her company and be someone she could talk to for a little while if she wished.

I had been thinking about Linda since I had met her. In many ways the necessity of having to physically go to the hospital to find and talk with her had led to an encounter that had stayed with me. I was touched by having been there, holding her hand and hearing her end of life wishes. I phoned the ward 10 days after my visit to see how she was getting on, and

was told that she had died. I wasn't surprised at this news, and felt sad to hear that she had died.

Linda had no immediate family and I had never successfully made contact with a carer I could interview about her care. Linda had a neighbour called Sue, and they were very close. I'd made a number of attempts to contact Sue but she had never returned my calls. I decided I would call Sue to pass on my respects, and I also felt an obligation to make sure the funeral wishes that were shared with me, were known. Much to my surprise, I managed to make contact with Sue, and she wanted to meet with me to tell me about what had happened to Linda. It became clear that she hadn't been able to talk previously due to the demands of working fulltime and being a carer to Linda.

Whilst I had been assuming that Linda had continued to become frailer before dying, Sue had a different account to share. Following my last visit with Linda she continued along that variable pattern of highs and lows of heart failure, but actually continued to gain strength rather than deteriorate. She had improved to the point where she, along with her health professionals, started to plan for her discharge back to her sheltered accommodation. A few days before she was due to be discharged back home, Linda had slipped in the hospital bathroom and had broken her hip. Linda had to wait for four days to have surgery on her hip, and the surgery had not gone well.

Sue described how she had received a phone call from a nurse on the ward to let her know that Linda wasn't very well following the surgery. Sue described how the nurse told her that Linda had been overdosed, explaining that Linda had been given painkillers that she wasn't able to process due to her renal failure. This had led to dangerous level of toxins in Linda's system.

I said what's happening here, and she went 'well there's not any easy way to say it but she's been overdosed'. I went, 'sorry?' She went, 'overdosed on painkillers'. I went, and how do you work that out, because it's a hospital. She went 'oh well it's orthopaedics fault because she's had the fracture they've overdosed her on painkillers, but not realising she's a dialysis (patient) who can't get rid of the toxics in her body like you and I can and needs the dialysis to help her but they didn't realise...'. (Sue)

Sue called the ward back, and was told by a different nurse that Linda was doing fine, sitting up in bed eating soup and there was no need to be worried. Sue decided to go into the ward to see how Linda was for herself, and found Linda very unwell and upset. From this point, Linda had been transferred to the Immediate Care High Dependency Renal ward, where she was given antidotes, dialysis and blood transfusions to try to save her life. Sue had been by Linda's bedside constantly. Linda's nephew, who she knew far less well (she had, for example, not nominated him as a carer I might talk with), had come in to be with her. Sue had just gone home for some rest when the phone rang to say Linda had taken a turn for the worse. By the time Sue got back to the hospital Linda had died. I was saddened and shocked to hear about what had happened to Linda. Sue described Linda as being 'bright as a button' one day, to dead within one week.

Linda was a participant I found difficult to keep tabs on. She didn't have much in the way of next of kin or carers for me to keep in contact with. The carer she did have was not a family member, which meant she wasn't always called quickly or given information by health professionals, despite being described by Linda as the daughter she never had. Sue knew that Linda was not very well in general, but she felt that it hadn't quite been the right time or circumstances for Linda to die.

I felt that Linda was an example of someone who could disappear and become subsumed by the systems of care around her. She didn't have people around her to help negotiate her relationships with professionals. She was, to my mind, more vulnerable for this. She also became a collection of diagnoses, symptoms and organs; a broken hip, worn out kidneys, failing heart and depressed. The system of care that dealt with the broken hip introduced a toxin to her system with fatal consequences, and the potential of this damage which would not be apparent unless all of her different diagnosis and parts of her body were taken into account. It seemed that Linda had become a collection of symptoms and parts, and this had contributed to her death.

1.1.2 Understanding Linda's Un/Predictable Dying

The circumstances of Linda's death raised a number of issues. What were my obligations to Linda and Sue in relation to this account of a potential critical clinical incident? I felt shocked by Sue's account of Linda's death and that there were potential ethical obligations I needed to consider. I decided to do two things. The first was to produce a full and non-anonymous transcript of my discussion with Sue, for her to have to use in any way she might like. Sue was considering if she would raise a complaint, although she felt that as non-legal kin this might not be an option available to her. My second decision was to initiate a conversation with my research steering group and seek further guidance on what ethical obligations we might have collectively, following the disclosure of this story.

The steering group consisted of a range of people, including a GP, a palliative care consultant, cardiologist and social researchers. I took Linda's story to them and asked for their advice and guidance about if I had any obligations as a researcher hearing about this potential incident, and what we might do to offer any support or advice to Sue. Following raising this story with the steering group there were a number of things that happened that left me with a sense of dismay. The first was the comment from one member of the group of, *'orthopaedics, at it again'*, as if this was a regular and known event. The second was concern being voiced that any association of the research project to a complaint about clinical practice would be bad for the study recruitment, and at this stage there were still many patients to recruit. The third was the passing of Sue's details to a clinician member of the steering group. This clinician had a clinical position which would allow her to make enquiries about the situation and deal with this potential complaint directly.

It sunk in slowly, that my ethical intentions and commitment to good practice, my desire to do right by Linda, led to me, due to my relative lack of seniority, to pass on the dealing of this 'situation' to a more senior, clinical professional who had identified the potentially disastrous consequences of this situation for the study. I had assumed that I had independence and agency as a researcher, but realised quite quickly that this assumption meant that despite good intentions, I passed on my relationship as the primary contact to my participants, with the most knowledge of Linda and Sue, to other members of the research team. It was now no longer my role to have contact with Sue about her concerns. The clinician investigated what had happened and wrote to Sue. She refused to ever reveal

the content of that communication. I never learnt what happened, apart from learning that a complaint was never raised. I don't know that the wrong thing happened, but I do know that I participated in the potential reduction of Sue's choices. At the very least I put her in a position where she was given guidance by a clinical professional with the power to resolve a potential complaint, but who also potentially held a conflict of interest in relation to her role on the research project.

At this point in the research project I also noted a change in the way in which I would position myself in relation to the research process or participants. I began to keep two versions of field notes, one for me, which would remain private, and another edited and shorter version, that could be made available to the wider research steering group. I began to edit out myself, and anything that could be perceived as controversial. I began to speak to the power of the 'data' as opposed to the role of my own perspective and process of sense making. The incident involving Linda's story served to position me as relatively less powerful than those I worked for. The self-silencing of my own point of view thereafter served to strengthen the notion of data as transcripts, removing non transcript interactions, non verbal data and the participation of my own subjectivity or reflexivity in the research process.

This event was transformative for me and it served to highlight a number of things, including what Linda's experiences had to say about heart failure and how much of it related to many other experiences people shared with me. It also served to show what the more serious consequences can be of being vulnerable and medicalised in the face of many different systems. It was an important event for me personally, as I was sharply reminded of how in conducting research I am also part of the system of medical care. I may sit face to face and interact with a participant during an interview, but I too am serving an interest in seeking that story, in advancing a research project, developing a thesis, taking knowledge that will be used to make certain points or arguments. I realised I was embedded in a context where the interests of others can be expressed through me, even if they are in opposition to my values or intentions.

Linda's experience was possibly the most problematic for me personally in undertaking this research, but in some ways it was not unique. In my view, Linda became individualised, where she, and her experience, came to be understood in a way that removed her from her context as a whole person who was part of a community, but in contrast was seen as a series of symptoms, diseases, or organs. This potentially influenced the type of patient she

was perceived to be, and the care she received. This thesis will explore how the systems of medical practice and research produce several kinds of patients, such as standardised patients who define the norm of being a patient living with heart failure; the patient leading a daily life with heart failure, the compliant or rebellious patient in hospital settings, the patient who manages her symptoms, or not, as per self care instructions and the patient who does not know he is dying. These patients appear as lacking insight and knowledge. However, there is also a fragmented patient, where heart failure becomes a collection of symptoms to the point at which the person themselves become invisible. Together, these factors come together to deny people living with heart failure, and professionals, the means to communicate as persons, with insights, knowledge, doubts and fears to discuss how to manage a condition that disproportionately hits socio-economically disadvantaged people (and women more than men among these). These influences and factors come together as structural violence, perpetrated by professionals without their intentions, but acting upon and shaping the experiences of people living with, and dying from, heart failure.

In this thesis I will next present a literature review, which will critique existing research and then in Chapter two, outline the methodological approach I have taken to address these issues, being that of structural violence. The findings will start at Chapter 3, at the level of individual experience of their everyday life with heart failure, and then open out to consider in various ways the context in which these descriptions have been produced and what that means for our interpretations of experience. In the course of the argument, features of the care system and how this links to the problematic of individual experience will increasingly be drawn in. I will also show how I have mined my data and developed my argument in a constant conversation with a range of theoretical perspectives, such as performativity (Butler, 1999, 2000, 2005) in Chapter 4, and Foucault (1977) in Chapter 5. In Chapter 6 I go on to explore aspects of relationships and care, illustrating the importance of institutional practices highlighted by approaches such as institutional ethnography (Smith 1999, 2005), and go further to show how those practices become expressed in relation to the idea of unpredictable dying in Chapter 7. I will end, in Chapter 8, with a discussion of how I pull these theories together in a consideration of structural violence.

1.2 Review of the Literature

This thesis brings together two areas of inquiry; that of the experience of living with heart failure, and how the field of structural violence may contribute to our understanding of living with heart failure. The experience of living with heart failure is one that has been increasingly researched and described in the literature, and here I review the current literature on living with heart failure. In this review I critique the tendency for research to individualize the experience of people living with heart failure, and comment on the role of methods in that process. In particular the areas of knowledge about heart failure, self-management and dying and heart failure will be reviewed and critiqued. Additionally, whilst there is a growing and extensive literature on the experiences of people living with and dying from heart failure (Welstand, Carson, & Rutherford, 2009; Yu, Lee, Kwong, Thompson, & Woo, 2008), there is a paucity of information on how patient experience relates to the context of their lives, including the socioeconomic conditions in which people live.

I will then go on to review the literature on the overarching theoretical framework in which this work was conducted, that being structural violence (Farmer, 2004; Farmer, Nizeye, Stulac, & Keshavjee, 2006). In particular I will consider the challenge of applying structural violence, which is a framework often used in the context of infectious disease, to the area of chronic disease. I will explore how different methods might be engaged to further understand structural violence, such as institutional ethnography, Foucault, post-colonial perspectives and performativity.

Finally the relationship between heart failure and structural violence will be explored. The approach of structural violence offers an perspective we can use to explore not only how socioeconomic circumstances impact patient experience, but also provides a way to consider how the medical system itself works to shape patient experience itself.

1.2.1 The Experience of Living with Heart failure

Heart failure is common, serious and heavily influenced by the socioeconomic context of people's lives. Heart failure is one of the only cardiac conditions that is on the rise in Scotland (Scottish Government, 2008). In the United Kingdom, heart failure can be as 'malignant' as most forms of cancer (Stewart, MacIntyre, Hole, Capewell, & McMurray, 2001). There is a one in five lifetime risk of developing heart failure in the UK (Lloyd-Jones et al, 2002), and it comes with a poor prognosis, in that 40% of people who develop heart failure will die from the condition in the year following their first hospitalisation with the illness (Blackledge, Tomlinson, & Squire, 2003). One out of three adults over the age of 55 will develop heart failure, and as few as 35% of people live longer than 5 years post diagnosis (Bleumink et al., 2004). Recent estimates are that around 40,000 men and 45,000 women are living with heart failure in Scotland (Stewart, et al., 2003). People on lower incomes are not only more likely to develop heart failure, but will likely die faster from it (McAlister et al., 2004).

Heart failure has long been recognized as a serious condition; yet understanding what constitutes a diagnosis of heart failure has been a subject of debate. There are many ways to describe what is commonly called heart failure in the UK, congestive heart failure in the US, and cardiac insufficiency in Italy. There is still debate about if it would be better called 'cardiac impairment' (Lehman, Doust, & Glasziou, 2005) due to the confusion caused for patients about the words 'heart failure'. The condition itself has been described throughout history, including by ancient Egyptians. The Romans used foxglove as a form of treatment for what we now describe as heart failure (Davis, Hobbs, & Lip, 2000). William Withering advocated a treatment for symptoms of heart failure as early as 1785, after obtaining a secret remedy from an old woman healer.

'I was told that it has long been kept a secret by an old woman in Shropshire, who had sometimes made cures after the more regular practitioners had failed. I was informed also, that the effects produced were violent vomiting and purging; for the diuretic effects seemed to have been overlooked. This medicine was composed of twenty or more different herbs; but it was not difficult for one conversant in these subjects, to perceive, that the active herb could be no other than the Foxglove'.
(Aronson & Withering, 1985, page 268, citing p2 of 'Account' by William Withering)

Knowledge about heart failure has grown along with knowledge of the circulatory system and of the heart, but it was as late as 1995 that the European Society of Cardiology published guidelines on diagnosing heart failure (Davis, et al., 2000). There are a number of ways to define what heart failure is in terms of the clinical symptoms that might constitute the condition (Davis, et al., 2000). Definitions commonly include features of ventricular dysfunction, impaired circulation or pumping of blood by the heart, limitation on exercise capacity and shortened life expectancy (Davis, et al., 2000). Heart failure itself is a term that describes a range of symptoms and deterioration of the heart, although it is not always consistently defined (Vilaseca, 2008).

CHF is a common syndrome, a manifestation of underlying heart disease, like anaemia, thyroid disease and damage to the heart muscle by ischemia (myocardial infarction) or hypertension. There is no universally agreed definition of CHF.
(Vilaseca, 2008, page 4)

Despite the disagreement about what heart failure is, the progression and the seriousness of the condition are quite clear. The progression of heart failure can be long gradual process, often with a history of underlying heart problems leading up to the point at which heart failure was diagnosed (Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008; Thornhill, Lyons, Nouwen, & Lip, 2008). Living with heart failure causes the heart to work increasingly harder in order to provide the oxygen required for the body to function. Eventually heart failure results in death, from the heart stopping or commonly related conditions, such as renal failure or pneumonia.

In more recent years there has been a growing interest in heart failure by researchers concerned with understanding patient experience. Daily life with heart failure is described in the literature as living with a range of challenging physical symptoms, including difficulties breathing, fluid retention, fatigue, pain, dizziness and irregular heartbeat, both in this research and in the literature (Rodriguez et al., 2008; Ryan & Farrelly, 2009). The literature also describes how these physical symptoms vary over time, becoming increasingly severe with deterioration and leading to a greatly decreased quality of life (Murray et al., 2002; Rodriguez et al., 2008; Ryan & Farrelly, 2009). Across the literature, an extensive range of invasive cardiac procedures, surgeries, and managing large amounts of medications, was reported as a common experience for people living with heart failure (Rodriguez et al., 2008; Selman et al., 2007).

There has been increasing interest in better understanding how people living with heart failure and their carers respond and cope with these increasingly complex limitations or needs. The increasing limitations and challenges can lead to feelings of frustration, loss, anger and isolation (Falk, Wahn, & Lidell, 2007), Murray et al., 2002; Ryan & Farrelly, 2009; Selman, et al., 2007; Thornhill, et al., 2008, (Waterworth & Jorgensen, 2010). The literature also reports dealing with thoughts about dying (Falk et al., 2007; Waterworth & Jorgensen, 2010). Partners also reported an experience of having an emotional balance of hope and despair in relation to coping with partner's illness, and described a loss of daily activities together due to dealing with the partner having many daily symptoms (Imes, Dougherty, Pyper, & Sullivan, 2011). People living with heart failure often have one or more comorbid illnesses they are also managing alongside the challenges of living with heart failure, such as diabetes and COPD (Rodriguez et al., 2008; Selman, et al., 2007). However there is a paucity of literature on patient experience of heart failure in relation to the role of inequalities, despite the impact on both the likelihood of developing or dying from heart failure.

There has been less interest in the ways in which the broader context of patient's lives impacts living with heart failure. Some work has considered the financial consequences of living with heart failure, including increased costs, and unplanned early retirement have been reported (Horowitz, Rein, & Leventhal, 2004; Rodriguez et al., 2008; Thornhill, et al., 2008). One US study on heart failure identified the financial barriers to receiving treatment, from having inadequate health insurance making it difficult to seek medical care or obtain the necessary medications (Horowitz et al., 2004). The study quotes one participant as saying '*Like I say, I just feel that I am stonewalled now, not by my medical condition, by my social condition...*' (Horowitz et al, 2004, page 636). There remain gaps in knowledge beyond individual coping, such as the impact of financial circumstances on patient experience. Much more that could be done to explore the broader context of the experience of patients, including the social, cultural, institutional and economic circumstances that interact with living with heart failure.

Despite the limitations of the knowledge about the experiences of people living with heart failure, summative reviews and explanatory models have been proposed based on current research. While much literature reported on the experiences of people with heart failure, some also has explored conceptual models for understanding the experience of living with heart failure. An example of this is the work of Buetow, Goodyear-Smith, and Coster (2001),

who suggest a framework of four coping strategies; avoidance, disavowal, denial and acceptance, for people living with heart failure. They suggest patients might have a dominant way to cope, but use a mix of strategies (Buetow, et al., 2001). Several key reviews have synthesized the findings from such studies (Welstand, Carson, & Rutherford, 2009; Yu, Lee, Kwong, Thompson, & Woo, 2008). Welstand, Carson and Rutherford (2009) conducted an integrative literature review of 18 qualitative studies exploring the experience of people living with heart failure. This review highlighted five conceptual categories of: diagnosis and manifestations of heart failure; day to day life; coping; role of others; and concept of self (Welstand, et al., 2009).

Further reviews reinforce this limited view on individual experience and along with it a growing sense of consensus on what constitutes the experience of people living with heart failure. Yu et al (2008) considered 14 studies focusing on heart failure. This review reinforced the idea of a growing consensus in the research on heart failure, describing it as leading to a poor quality of life, as debilitating and distressing, contributing to many negative physical and psychosocial experiences. The authors also report that older people have difficulties understanding their illness, and that this negatively impacts on their successful adjustment to living with heart failure. The review also highlighted the way in which the prospect of sudden death was very alarming and how social support was of importance (Yu, et al., 2008).

More recently (Jeon, Kraus, Jowsey, & Glasgow, 2010) conducted a narrative review of papers published on qualitative research on heart failure, considering 30 papers published between 1990 and 2008. Similarly to previous reviews the authors documented a summary of the experiences of life with heart failure. These were broken down into impact on daily life, coping strategies and care or service delivery. The aspects of daily life that were reported on as emerging from the published literature were social isolation, fear and the loss of a sense of control. In relation to coping strategies, the value of sharing experience and the process of adjustment to change were outlined as important parts of the experience of people living with heart failure. These findings largely resonate with previous reviews (Welstand et al, 2009; Yu et al, 2008).

When broader context is considered, concerns about lack of consideration of the patient's context emerge. Jeon et al's (2010) review is somewhat distinguished by addressing the literature on care or service delivery, which considered the role of relationships, comorbidity, knowledge and health services (including access and continuity). Jeon et al

(2010) commented that there was a need for further development of theoretically informed ways to consider the experience of heart failure in relation to the influence of age, gender, culture and socioeconomic status, noting that such context was a gap in the literature.

This lack of context in research has been an identified issue in cardiac health research, particularly in relation to the under-representation of women studies. This is reflected in the reviews of heart failure studies focusing on patient experience, and it highlights how there are issues with who the studies on people with heart failure collectively represent. The review of 18 such studies by Welstand et al (2009), illustrates how 245 patients were included, but only 73 of them were women. 24 of those women were represented in studies on women only, and the rest were distributed across the remaining studies, often significantly outnumbered by the male participants. This lack of gender representation in qualitative studies is well known in relation to studies on coronary heart disease in general, and is considered to be influential in gendering our view of the experience of living with coronary heart disease (Emslie, 2005). Yu et al (2008) do indicate there may be differences in coping with heart failure by gender, but draw the conclusion that women may be better at accepting their limitations in living with heart failure and therefore report fewer difficulties. However this also overlooks the way in which women are under-represented in studies.

Additionally, ethnicity and socioeconomic status of research participants also seems unclear, and perhaps underrepresented. Welstand et al (2009) report on the ethnicity of participants, but do not provide an overall summary of this much smaller number of participants again, and the issue of socioeconomic status is not reported upon at all. The data on the participants appears to not always have been made available in the original studies, perhaps highlighting a need for better rigour in the reporting of demographic information in qualitative research studies. (Jeon et al., 2010) also reports on the lack of detailed information on study participants, particularly in relation to socio-economic status, and argue there is much to be done to develop a better theoretical basis for understanding how the experience of living with heart failure interacts with age, gender, culture and socioeconomic status.

The lack of diversity of research participants is also reflected in the lack of diversity in research methods used in qualitative studies on heart failure. A main critique I will pursue of the current research into the experience of living with heart failure is that it is

overwhelmingly dominated by research approaches that use common methods, namely a thematic analysis of interview or focus group based studies, and lacks a diversity of sampling. The potential arises for reductionist and non representative accounts of the experience of heart failure to emerge. There is a strong case to be made that different methods and forms of enquiry would add to the knowledge and learning about heart failure, and that in turn, would help shed insights into patient experience. Ultimately, gaining such an understanding may be required in order to broaden thinking about improving care, self management and care for people with heart failure.

Summary

The medical field has a long and ongoing debate about what constitutes and defines heart failure. There are many different ways to describe what heart failure is, and confusion about what constitutes heart failure itself. It is clear though, that it is a condition that leads to a slow and unpredictable decline in health and can be more life limiting than many common cancers. It is a common and yet not well known condition, and socioeconomic circumstances influence the chances an individual will develop heart failure and how quickly they will die from it. In contrast, social researchers appear to be more quickly reaching a consensus about what constitutes the experience of people with heart failure. There are a growing number of qualitative studies being conducted on patient experience of living with heart failure and these are forming a cogent view of patient experience. Yet that view of individual experience is one that is outside of the context of people's lives, and draws on a limited diversity of people, and a limited range of methods. Very little is known about whom these studies describe, tending to render invisible the diversity of gender, class or socioeconomic status. The cogent view forming of patient experience is essentially reductionist, and doesn't address the diversity of the patients developing heart failure or the context of their lives. A broader view of the experience of living with heart failure is needed in order connect how we understand patients' experiences, and the context of their lives. Without this, we risk a view of patient experience that serves the way medical systems may act to shape that experience in a way that privileges the needs of those systems, rather than the needs of patients themselves.

1.2.2 Knowledge about heart failure

Heart failure is a condition for which there is little awareness about what it actually is, both among the general public and even for many people who are diagnosed with heart failure. Despite this being a common and serious condition, what it is like to live with heart failure is not well known by the general public. The SHAPE study, which explored the attitudes to heart failure across nine European countries, found that whilst 86% of participants indicated they had heard of heart failure, only 3% were actually able to describe what it was (Remme et al., 2005). It is common that even people who have heart failure know little to no information about their diagnosis (Rodriguez et al., 2008), with as many as 40% of patients not knowing their diagnosis (Buetow & Coster, 2001). Communication has also been reported to be poor with partners, who described a sense of information being concealed from them (Imes et al., 2011).

Despite being under-informed, people with heart failure are often reported as wanting more information and feeling confused about the limited information they do have. The literature shows that patients vary in the level of information they wish to know about their condition, and even when patients do know some information they do not always connect how it relates to their heart failure (Ågård, Hermerén, & Herlitz, 2004; Field, Ziebland, McPherson, & Lehman, 2006). Knowledge provides an important opportunity to engage in self-management, although many other factors will influence if a patient wishes to follow the advice of professionals (Ågård, et al., 2004).

Professionals however, may have concerns about the benefits of sharing information with patients living with heart failure. In 2005, a research study concluded that patients who were told they had heart failure reacted negatively, and that therefore, it could be bad for patients to tell them about their diagnosis of heart failure (Tayler & Ogden, 2005). Not only did patients react negatively when told that they had heart failure, they were more likely to perceive this serious condition as being serious (Tayler & Ogden, 2005). By contrast, those patients whose condition was described to them using euphemisms instead of the term heart failure were less likely to react strongly (Tayler & Ogden, 2005). Other research also suggests that patients might be harmed if distressed by information about heart failure, particularly if they do not wish to know about their condition (Ågård, et al., 2004).

Despite patients expressing confusion and wishes to know more information, professional reservations to talk about heart failure appear to lead to a range of alternative explanations for heart failure that may exacerbate this confusion. Tayler and Ogden (2005) asked GP's to rate what terms they were most likely to use to explain the problem of heart failure. The term most likely used was 'you have fluid on your lungs as your heart is not pumping hard enough', followed by 'your heart is a bit weaker than it used to be' and 'your heart is not pumping properly'. The term 'heart failure' was rated 7th out of 10 options. Not surprisingly, patients (and a sample much younger than the age people often are with heart failure) felt the term 'heart failure' sounded more serious and would have a more significant negative emotional impact than the euphemism 'you have fluid on your lungs as your heart is not pumping hard enough'. The researchers' conclusion was that it is reasonable for practitioners to use euphemisms, as it will avoid causing upset (Tayler & Ogden, 2005).

One possibility about the lack of quality information sharing is that professionals themselves may have some confusion about what constitutes heart failure too. Not only are people living with heart failure under-informed about their condition, it appears there is a range of misconceptions from professionals about how heart failure could be managed, with professionals showing a poor understanding about medications that prolong life and improve the quality of daily life (Remme et al, 2005). Overall the quality of care provided to people with heart failure is poor, and up to 50% of all heart failure patients throughout Europe do not receive adequate and essential treatment (Remme & Swedberg, 2001). The consequences of poor treatment are unnecessarily high mortality rates and distressing hospital admissions (Gustafsson & Arnold, 2004).

Some of the uncertainty about heart failure reflects a lack of professional engagement in available knowledge about the condition. In Scotland, medical professionals can learn more about heart failure through drawing on the guidelines published by the Scottish Intercollegiate Guidelines Network, or SIGN (2007), however one study indicated that as many as 40% of a sample of Scottish GPs indicated they hadn't read the guidelines, despite being aware of them, and even for those that had heard of the guidelines, that didn't appear to impact the level of knowledge for a sample of evidence based therapies (Leslie, McKee, Imray, & Denvir, 2005). There was both an indication of sub-optimal use of some medications and GPs reporting a lack of confidence in diagnosing, with one being cited as saying 'we know we are wrong 50% of the time' (Leslie et al, 2005, page 325).

The sharing of information appears to be influenced by social, cultural and institutional factors. The sharing of diagnostic information can also be driven by organisational factors. In New Zealand the diagnosis of 'congestive heart failure' must be indicated on pharmacy labeling with the prescription of certain medicines in order to allow full subsidies on their prescription costs (Buetow & Coster, 2001). Who is told their diagnosis may also be shaped by other population factors. Buetow and Coster (2001) found that a disproportionate number of ethnic minorities had the poorest understanding of their condition. One US study recruited heart failure patients who were New York Heart Association Grade II, which is one indication of the much earlier disclosure of diagnosis in US settings, and participants were actually asked about their 'heart failure' (Rodriguez et al., 2008).

The issue of information sharing is appears even more complex in relation to discussing prognosis. The literature indicates that patients, who don't know information about their prognosis, often reported a desire to know more (Rodriguez et al., 2008; Rogers et al., 2000). Partners of heart failure patients have also been reported to want more information about heart failure, including information about treatments, prognosis and life expectancy, and those that did get that information, were pleased to have it (Imes et al., 2011). Goodlin, Quill and Arnold (2008) advocate for a patient centred approach to communication about diagnosis and prognosis, modelled from patient centred approaches that are used in relation to other illnesses. This approach suggests a planned method of communication well in advance of serious illness, that favours using plain language, initiating discussions about preferences for information and patient expectations in regards to participation in decision making, clarifying the values and goals of care, actively asking patients what they know and would like to know and offering empathetic responses (Goodlin et al, 2008). Similar strategies for enhancing communication with patients were also advocated by Rogers et al (2000). These strategies might reduce the shock of discussions about decline in heart failure, or the nearing of the end of life, as much has been discussed and established already (Goodlin et al., 2008).

There is a need to broaden the perception about when it might be appropriate to talk about end of life issues, and finding ways to improve communication is essential for improving patient involvement in end of life decision making. Communication about prognosis orientates around the predictability of dying and some advocate sharing the prognosis if it is felt the person might die within the year (Goodlin et al., 2008). Buetow and Coster (2001) recommend the use of advance directives regarding what information patients might want to know about diagnoses and prognoses, and for that to be clarified

before patients become seriously unwell. One study highlighted the tension in engaging patients in informed consent about treatment options when they may not have been informed of their diagnosis, and quote a nurse reflecting on this dilemma ; *'if they don't know what they've got then how can anyone make decisions'* (Sanders, Harrison & Checkland, 2008, page 105). Clark et al (2009) reinforce this concern, but whilst knowledge is required for self-care they point out that knowledge is not all that is needed, and other issues such as patient views of professionals as being responsible for managing health conditions, and a consideration of the wider values and context of a person's life is also important (Clark et al., 2009).

Summary

Many patients are not aware of their diagnosis of heart failure, and carers also report a lack of information about heart failure. There is a sense that having knowledge about your condition might be helpful for participating in self-management. Yet this information is quite complex and often it is hard to connect the condition of heart failure to the symptoms experienced. There is some reluctance among professionals to share information about heart failure, for fear of causing upset. Many euphemisms are used instead, perhaps adding to this confusion already caused by the complex relationship between the condition and the symptoms. Patients are mostly seen as wanting more information about their condition. Knowledge is also variable among professionals, who may not always feel well equipped to provide appropriate care.

Sharing information about prognosis is also fraught with problems. There are many difficulties in predicting the trajectory of the condition, and this appears to exacerbate the barriers to sharing information. Some researchers have pointed out the paradoxical situation of under-informed patients not necessarily managing their disease as professionals would wish, or having made end of life wishes known. The professional is privileged in this relationship as the holder of the knowledge, yet may be lacking knowledge themselves. Rather than expose this lack of knowledge, either about heart failure treatments, or the lack of predictability about dying, information is withheld and justified as being withheld to avoid harm to patients. This paradoxical situation around information sharing, highlights how institutional processes in care can have much influence in shaping the patient experience.

1.2.3 Self-management

Self-management can be viewed as how well an individual complies with professional views and advice on managing an illness. Professionals encourage self-management as being important to living well with heart failure. However it has been pointed out in the literature, that self-management often has specific, professionally defined parameters also. Leventhal, Riegel, Carlson, & De Geest (2005), define compliance with self-management as *'the patient's informed free choice of behaviours selected from those recommended by the healthcare provider'* (page 299), with professional responsibility to provide knowledge, skills and motivation and patient responsibility for gaining skills, implementing the advice and seeking help when required. The contradictions in the idea of free choice from a limited list of options, highlights how the term 'self-management' is heavily embroiled in professionally directed behaviour, and may accurately be used to describe patient-professional partnerships (Leventhal et al., 2005).

People living with heart failure are often identified as not following professional recommendations for self-management. The literature does identify that compliance with self-management is an issue in heart failure (Rodriguez et al., 2008). One study explored the level of self care in developed and developing countries and found self care was lacking in both settings, with some indication of greater levels of variability between self care management, maintenance and confidence in developing counties (Riegel, 2009). However it has been noted that patients are motivated to avoid hospitalizations and reduce symptoms, but face barriers in complying with self-management, such as finding dietary and liquid restrictions difficult, or not being able to afford fresh fruit and vegetables (van der Wal, Jaarsma, Moser, van Gilst, & van Veldhuisen, 2010). However most did try to make changes to their lifestyle and the researchers highlight the need for self-management interventions to be tailored and meet individual understanding, expectations and beliefs (van der Wal, et al., 2010).

It may be difficult for people with heart failure to engage in self management if they have limited information about their condition or how their symptoms are related to heart failure. The way in which people might talk about other causes for their heart failure was noted by Horowitz et al (2004). Without an explanation for their heart failure, the authors suggest that patients will find alternative labels for their experience of symptoms, attributing it to other causes, either disease or social causes (such as stress). They suggest that in the absence of information it is highly reasonable for patients to look for alternative

explanations and those may be external factors. They go on to explore how improved patient education might correct this, through providing a more coherent representation of heart failure (Horowitz et al., 2004). However others argue about the importance of such social causes. Leventhal et al (2005) have proposed, following an extensive review of the literature, that compliance in heart failure needs to take into account a broad range of factors that include socioeconomic factors, aspects of health care systems, the extent of the condition itself, treatment options and the patient's experience. An example of considering the broad aspects of a patient's experience can be found in the context of work on experiencing heart failure in a rural setting by Clark et al (2009). They argued that the values of rural life impacted on self-management, with participants in their research seeing symptoms as being as predictable as the weather and crops, and that made it harder to see heart failure as something that could be managed (Clark et al., 2009).

Non-compliance with self-management particularly impacts certain groups of patients. Low income heart failure patients are reported in the literature as being less likely to comply with self-care (Macabasco-O'Connell, Crawford, Stotts, Stewart, & Froelicher, 2008). The authors argue this is due to lower education, low to poverty level incomes, multi-morbidity, and the extreme stress that resulted from dealing with such life challenges (Macabasco-O'Connell et al., 2008). Economic hardship has been described as severely limiting the ability to take required self-care such as purchasing healthy foods, transport and access to exercise (Jeon, Essue, Jan, Wells, & Whitworth, 2009). At most risk of non-compliance were those who had multi-morbidities, and those living just above eligibility for state benefits and minorities (Jeon et al, 2009). However as there remains a lack of any research on the role of socioeconomic situation on patient experience, much remains to be learned about the relationship between self-management and socioeconomic status.

Lack of knowledge, in combination with social and cultural context, influences compliance to self-management. The literature reports that inadequate knowledge about heart failure can lead patients to fail to connect their condition with their symptoms, which can have serious implications for the idea of self-management, or help seeking during deterioration (Horowitz et al., 2004). However others argue that self-care not determined by knowledge alone, but maybe influenced by experience and views on professionals and services, with feeling that doctor knows best, inhibiting confidence for self care (Clark et al., 2009). In the study of rural patients conducted by Clark et al (2009), the context of working on the land was also seen as leading to delays in help seeking with valued traits such as stoicism and self-reliance. This suggests the importance of being responsive to patient context and how

that might shape views and attitudes to illness. Likewise some argue about the role of self-efficacy, illustrating that low self confidence is connected to low level of knowledge of self-management (Meyerson & Kline, 2009).

Gender is not thought to influence compliance to self-management for people living with heart failure. No differences have been reported between men and women in relation to ability to participate in self care for their heart failure (Lee et al, 2009), however there have been reported differences between men and women in relation to risk for poor self care that could be important to support better patient education. In general and for both genders, being older, and better educated were predictive of better self care. Education was even more predictive for improved self-care for women (Lee et al, 2009). The gender influences of risk for poor self care for women, were being married and having diastolic heart failure, for men risk was related to having multi-morbidities and being newly diagnosed (Lee et al, 2009).

Managing more than one medical condition is thought to influence self management. Attitudes to self care are complicated by the need to prioritize competing conditions or priorities (Dickson, Buck, & Riegel, 2011; Jowsey et al., 2009; Meyerson & Kline, 2009; Yen et al., 2011). Dealing with a range of conditions can make it more difficult to identify symptoms or ask on risk factors (Dickson et al., 2011; Jowsey et al., 2009). This might be particularly the case when the comorbidity is depression (Jowsey et al., 2009). Comorbidities can mean the involvement of multiple health care professionals, leading to fragmented self-care instruction, through seeing too many specialists and the information either conflicting or not being well integrated, for example, reconciling multiple diet restrictions for each condition (Dickson, Worrall-Carter, Kuhn, & Riegel, 2011; van der Wal, et al., 2010).

In relation to medication management, there can be confusion about what medication is for which symptoms. It was reported that patients frequently thought medications for heart failure were often for different conditions, such as with diuretics, which might be seen to reduce swelling, rather than addressing fluid retention on an ongoing basis. This leads to a lack of participation in prevention of difficulties, or addressing times where there is a decline in condition (Horowitz et al., 2004). It can be challenging for patients to comprehend complex medication regimes, leading to compliance issues with medication (Field et al., 2006; van der Wal, et al., 2010; Yen, et al., 2011). Indeed only one study found that patients who were self adjusting medications as part of self management, were

atypical, being highly educated or retired health professionals (Field et al., 2006). One study illustrated that patients indicate a need for ongoing support for information about medications, where nurses might feel that patient education is something that is achieved and not needed on a continuing basis as nurses felt patients were more informed than the patients themselves did (Ekman, Schaufelberger, Kjellgren, Swedberg, & Granger, 2007).

Much effort is made to engage patients with self-management, and much of this focuses on how to increase patient participation in managing their symptoms in the way professionals advise. Some argue that specialist roles, such as case managers, may have time to better identify psychosocial barriers to care, and engage in better relationship building with patients (Olbort et al., 2009; Peters-Klimm et al., 2009). This would address the time constraints that may limit GP consultations (Waterworth, Gott, Raphael, & Barnes, 2011). GP's themselves acknowledge that heart failure patients might require more time, and taking the time to talk with patients may increase compliance with treatment (Waterworth, et al., 2011). Yen (2009) argues that professionals tend to have the perception that patients have failure to comply or services are fragmented, where patients are more likely to think of their own individual challenges as barriers. They suggest that professionals have an over reliance on their own perspective when it comes to thinking about service improvement, and call for more involvement of patient perspectives when thinking of how to improve care and update of self care (Yen, et al., 2011). Patients themselves have expressed that there are barriers to providing adequate heart failure care due to a lack of confidence in diagnosing heart failure, reluctance to follow evidence based treatment guidelines and a lack of integration across primary and secondary care (Fuat, Hungin, & Murphy, 2003).

Professionals engage in a range of strategies that focus on trying to get patients to comply with their recommendations. Specialist nurses may be perceived to increase self care, and Sanders, Harrison and Checkland (2010) argue that specialist nurses try to personalize protocol driven care, through patient education on relevant lifestyle issues. Such nurses also were described as trying to normalize patient experience, or offering a sense of a common experience (Sanders et al, 2010). Authors argue that these strategies in combination serve to reduce the patient ability to negotiate other options, including that of no treatment, which is very rarely discussed in the literature, and comply with evidence based guidelines. This highlights a tension between providing patient centered care and protocol driven care based on evidence (Sanders et al., 2010).

A further strategy used to encourage compliance is to present patients with scientific information, leaving the patient the job of negotiating with science, rather than being a discussion with the individual professional. Cardiologists and heart failure nurses have been reported in the literature to draw on knowledge from randomised control trials, as a cornerstone for knowledge about heart failure, potentially compromising patient choice and autonomy (Sanders et al, 2008). Patients debate their options with evidence based medicine, and not with their individual practitioner about their individual circumstances (Sanders et al., 2008). Sanders et al (2008) argue that the focus on symptoms can then objectify both the patient and the professional, as discussions between them focus on symptoms and evidence gathered from randomised control trials.

Debating with evidence based medicine can depersonalize conversations between patients and professionals, it also reflects knowledge that tends to privilege certain groups of patients. The concern about the reliance on evidence gathered from randomised control trials is how they have focused on left systolic function as a criterion for entry into research trials (Lehman et al., 2005). The population this criterion best fits is younger men, which means research evidence and clinical definitions have become weighted in the direction of that population, potentially at the expense of older people with heart failure and women (Lehman et al., 2005). Lehman et al (2005) argue for a change in the diagnostic tests, as a way to better describe a broader population of people. This does highlight that the symptoms that objectify people with heart failure may be influenced by the evidence base that professionals rely upon to promote self-management, which in turn may be biased by the focus on younger men being seen as preferable trial participants. Research exploring the reasons for people with heart failure to participate, or decline, taking part in research such as clinical trials found that people declined participation due to being too old, too ill, lack in mobility and transport problems (Lloyd Williams 03). Sociodemographic factors were not found to be significant, but being younger, male and in better health was related to increased willingness to participate in research (Lloyd Williams 03).

Resistance to professional discourses can lead to increased pressure by professionals on patients comply, drawing on what Hook (2004) describes as discourses that draw on power and knowledge to reinforce professional authority. In relation to heart failure discourses about symptoms, one study by Sanders et al (2008), showed how cardiology-based professionals (cardiologists and heart failure nurse specialists) draw on their interventionist approach and the power of evidence based medicine to try to encourage agreement with their suggestions to patients. Cardiologists described their goals of medication compliance,

and patient choice would be a focus on what medications they were going to take, not if they were going to take them or not (Sanders et al., 2008). Sanders et al (2008) described how cardiologists would draw on evidence based medicine, or studies, with the use of language such as 'we think..', indicating the authority behind the individual practitioner's views. Sanders and Harrison (2008) go further, describing professional roles as being discursively maintained. In their paper, they described how cardiologists, geriatricians and heart failure nurses drew on claims of specialised expertise to describe their roles (Sanders & Harrison, 2008). Overall there were four discourses of; expertise, competence, organisational efficiency and patient centeredness. Heart failure nurse specialists drew on a biomedical narrative alongside one that emphasised the caring, relational aspect of their role (Sanders & Harrison, 2008). Cardiologists just drew on the expertise discourse (Sanders & Harrison, 2008). Through this use of expertise, their role also becomes discursively maintained, which in turn offers the authority to reinforce the importance of discourses about symptoms with patients.

Summary

Self-management is an important part of maintaining health for patients with heart failure, and requires a patient to choose to participate, or even comply, with professional recommendations about self-care. There is much non-compliance in self-management in heart failure. Socioeconomic status seen as influential in non-compliance for a range of reasons, including barriers to affording some suggested changes (such as buying particular food), and having many competing demands. Different life contexts influence the way people view their health, and can impact views on self-management, but this is rarely acknowledged. It does however show a need for better congruence between patients and professionals about what heart failure is, how it is caused, or what it means, as one way to improve self-management adherence.

There are completing perspectives on self-management and reasons for non-compliance, with professionals often seeing patient failure, and patients seeing institutional barriers. Some argue that self-management illustrates how the medical system actively shapes patient experience, through normalization of experience, and seeking compliance to professional perspectives through strategies such as claiming the power of scientific research as a way to negotiate with patients. The drawback to this is that scientific research, be it on patient experience or randomized clinical trials, often privileges certain groups of patients as research participants. This means that scientific knowledge can suffer

from rendering invisible the contextual aspects of life, such as socioeconomic status, which is clearly an issue in relation to compliance. Self-management also tends to promote an objectifying focus on symptoms. There is much potential for self-management to lead to ways of discursively maintain the role of privileged expert professional. This further illustrates how patient experience continues to be shaped and influenced by the medical institutions, but in ways that overlooks the broader context of the patients life.

1.2.4 Dying and heart failure

Dying is a life event that has transitioned from being something managed by community and families, to being a medically managed experience. The idea of telling patients the difficult prognosis of dying, is one that has evolved over time. Armstrong (1987) describes the transition from withholding a prognosis of dying as being seen as a productive secret to preserve hope, into being seen as telling a lie. As the knowledge about dying became the terrain of medicine, as opposed to informal networks of friends, neighbours or family, it was now the medical world's responsibility to tell patients they were dying (Armstrong, 1987). Some researchers have argued that truth about the prognosis of heart failure can be told, and hope preserved at the same time, particularly if the idea of unpredictability itself, is offered as a way to maintain hope (Ågård, et al., 2004). However, it is recognised there is a need for greater support of training or skill development, for professionals in sharing the news that a patient is dying in more supportive ways (Department of Health, 2008).

Despite dying now being in the realm of medicine, medical knowledge about when people with heart failure might die is very limited and this may lead to professional reluctance to talk about dying. Dying from heart failure is broadly described as unpredictable (Boyd, et al., 2009; Goodlin, 2009; Murray et al., 2002), and this unpredictability is described by professionals as a key reason for not telling people about the seriousness of their condition, with consequences for how people with heart failure and professionals engage with the prospect of dying. While it may be very difficult to predict dying in heart failure patients, the question, 'would I be surprised if this person died in the next 6 – 12 months', did appear to hold validity for heart failure patients (Schneider, Oster, Hager, & Klindtworth, 2011). This also indicates the value of including palliative care alongside other care, including that of rehabilitation (Schneider, et al., 2011).

Despite the challenges in predicting death with heart failure, patients and carers do express a desire to talk about end of life issues. Even when patients and carers may lack awareness about the prognosis for living with heart failure, some literature indicates that both groups are very willing to discuss end of life (Low, Pattenden, Candy, Beattie and Jones, 2011). This willingness to talk about declining health and end of life was also described by (Waterworth & Jorgensen, 2010), who described a non linear process of adjustment, hope and fear, and concerns about increasing dependence on professionals (Waterworth & Jorgensen, 2010). Partners also reported a lack of conversation between partners about end of life wishes, and what extent to go to in order to prolong life, and less idea again if such wishes were made clear to doctors involved in care (Imes et al., 2011). End of life planning is an issue that should be addressed, including the deactivation of cardiac devices, which also was not discussed (Imes et al., 2011).

Carers may have particular needs in relation to talking about end of life issues with heart failure. Carers reported it was challenging to discuss end of life wishes with their partner, and only a few people had those discussions together (Small et al., 2009). Carers expressed a preference for death to be sudden and at home, some reported negative experiences of their family member dying in hospital settings, describing unhelpful attitudes or unnecessary interventions (Small, et al., 2009). Care to people with heart failure could extend beyond the patient dying to address the needs of carers, who may also be suffering physical health problems and are dealing with the emotional challenges of bereavement (Small, et al., 2009). Indeed the experience of what was considered a 'good death' was seen to be helpful for enhancing adjustment for carers post bereavement (Small, et al., 2009).

GP's show some reluctance to talk about the prognosis and end of life issues in relation to heart failure. In one study GP's were described as avoiding explaining what heart failure is, particularly if the patient is older, and had a reluctance to share prognosis (Waterworth & Jorgensen, 2010). For this same group of GP's palliative care was considered only when symptom management was no longer effective (Waterworth, Raphael, & Horsburgh, 2010). The authors suggested that some GP's could benefit from training on communication around end of life, and suggest that taking a life transition approach early on in heart failure, rather than waiting to start an end of life approach as the disease becomes more life threatening, might be a productive way to address issues relating to palliative care for heart failure patients (Waterworth, et al., 2010). Low et al 2010 also argue that

professionals need to consider improving communication skills and that a change in culture is needed to encourage earlier discussions about end of life (Low et al, 2010).

Professionals may lack knowledge or guidance about when and how to address end of life discussion in relation to heart failure, including when to engage palliative care services. The decision making strategies used by heart failure nurses for medication adjustment were compared in one study, to those for deciding if palliative care was required (Dowding, Spilsbury, Thompson, Brownlow, & Pattenden, 2009). There were far fewer clear processes for engaging palliative care. This lack of institutional processes may mean it doesn't happen as often as it could (Dowding et al., 2009). Palliative care could make an important contribution to the options for care at the end of life, for people with heart failure (Thompson, 2007). However open, careful communication about prognosis would be required in order to effectively engage palliative care in the end of life care for heart failure (Thompson, 2007). Some argue that palliative care should be integrated throughout care in heart failure, and include case management that can address mental and social issues, due to the high prevalence of these concerns (Bekelman et al., 2011). However it was clear that better coordination of care was needed across specialities in order to integrate palliative care more effectively (Low et al., 2010). Some suggest that palliative care for people with heart failure needs to be closely aligned with primary care, due to the role of primary care in meeting the vast majority of needs for this group (Goodlin, 2009).

Perhaps as a consequence to the lack of knowledge or discussions about end of life issues for heart failure patients, very few people with heart failure die in hospice settings. Of those that did in one US study, patients were significantly more likely to be white, widowed and women (Zambroski, Moser, Roser, Heo, & Chung, 2005). Interestingly the hospice patients reported symptoms were statistically no worse on the day of death, than the day of admission, which may signal the need to facilitate access to hospice earlier in order to gain more benefit from hospice care (Zambroski, et al., 2005). Additionally, there was some indication that medications to alleviate heart failure symptoms were being used at suboptimal levels, indicating the potential need for greater education of care for non-malignant diseases in hospice settings (Zambroski, et al., 2005).

There is a growing awareness that more could be done to improve communication, and options for care, for people dying with heart failure. The Scottish Action Plan, 'Living and Dying Well', suggests that greater awareness of the less predictable way people with heart failure reach the end of life, could be helpful for improving awareness of the use of end of

life care for such groups (Healthier Scotland, 2008). Much of this action plan relies on an initial step of identifying that a person is dying (Healthier Scotland, 2008), and this is a key challenge in the area of heart failure, particularly with such a strong discourse of unpredictable dying. There is some commitment to improve care, so that more people have choices about their care at the end of life (Department of Health, 2008), and how to make this meaningful to people with heart failure will be challenging.

The literature suggests that with good relationships, collaborative and shared care approaches could offer a useful way forward for increasing palliative care provision for people with heart failure (Thompson, 2007). The importance of multidisciplinary care was also highlighted in 'Living and Dying Well', as an important feature of improving end of life care (Healthier Scotland, 2008). However there are challenges to making this happen. Currently patients might enter one hospital system and encounter one approach, of trying to preserve life at all costs, or another, where the idea of keeping a person comfortable and allowing them to die might be the prevailing view. An example of this from the literature is the difference in the philosophy of care between cardiology, with a focus on extending life actively (Chattoo & Atkin, 2009), and palliative care, with its focus on facilitating the dying process (Selman, et al., 2007). When professionals hold a cure attitude to advanced heart failure, the literature reports it may make it difficult to engage in palliative care at the right time (Rogers et al., 2000; Ryan & Farrelly, 2009). The idea of sudden death, as in heart failure, is quite different to the way in which people might die from cancers (Chattoo & Atkin, 2009; Rogers et al., 2000). Rogers et al (2000) describe palliative care and cardiology as having different semantic, historical and practical aspects, which influence and shape their different perspectives on dying.

Summary

Dying has evolved from being a family and community matter to being one that is now the terrain of medicine. Despite this transition, it can be an uncertain terrain for medical professionals, who find tension between offering information about a prognosis and wishing to maintain hope for patients. Additionally, dying from heart failure is regarded as unpredictable, and this is often described as a reason to not share the prognosis. Patients and carers describe being open to conversations about dying, yet professionals may feel ill equipped to have conversations about the end of life. Some suggest a focus on having such discussion at an early stage of heart failure, and that emphasizing the uncertainty, might be beneficial.

The medical systems that work with people at the end of life, such as cardiology, gerontology, primary care and palliative care, can be highly fragmented, and there is only a recent emphasis on the importance of services such as hospice for non-malignant conditions. There is a need for increased education and linkages between different types of approaches to care that promote better relationships and collaborative care. There is a policy level commitment to patients having choice for end of life care, yet while patients remain uninformed about their prognosis, the choices made about end of life care remain the domain of the medical professionals rather than of patients themselves. Thus medical systems, already challenged with seeing patients outside of the context of their lives, serve patients in a way that obscures the context of the gravity of their condition. The outcome of this is that the medical system retains the knowledge and authority required to make essential end of life decisions.

1.2.5 Structural violence

Documenting the role of context, including socioeconomic context, and its subsequent impact on health and wellbeing is a serious challenge for researchers. In the majority of qualitative research on heart failure, there has been much focus on patient experience but very little inquiry into the role of inequalities, despite the well established disparities in prevalence and mortality. In this thesis I draw on the ideas of structural violence as one such perspective that is interested in the intersection between inequalities and health. Paul Farmer argues in his accounts of structural violence that the mechanics of oppression are easily seen in accounts of third world countries, where infectious diseases follow trails of war, destruction and oppression (1999, 2004). He argues that oppression, of political and historic origins, are expressed biologically, and thus the exploration of the biological expression of inequality provides insight into illness and the societal context in which both the illness and inequalities occur.

The phrase structural violence was coined by Johan Galtung, and has its origins in the liberation theologians of Latin America (Galtung, 1969), and describes the role of social structures that characterize the oppression of poverty and social inequality, including racism and gender oppression. Systematically exerted, structural violence forms a 'social machinery of oppression' (Farmer 1994, page 307), exerted by all through social order, ideas, values, all of which focus on the idea of praise or blame at the level of the individual.

If we cannot study structural violence without understanding history, the same can be said for biology. How does structural violence take its toll? Sometimes with bombs or even airplanes turned into bombs or with bullets. However spectacular, terrorism and retaliatory bombardments are but minor players in terms of the body count. Structural violence, at the root of much terrorism and bombardment, is much more likely to wither bodies slowly, very often through infectious diseases. (Farmer 94, page 315)

Farmer makes a compelling argument that in the backdrop of military force, extreme poverty and an oppressive history, the spread of HIV in Haiti is the voice of structural violence (Farmer, 1999, 2004). Farmer (1999, 2004) makes this argument in the context of infectious disease in Haiti, such as HIV and tuberculosis in Russia. Structural violence is an approach that has been used to explore a range of health and social issues in developing countries (Eldridge & Johnson, 2011; Ellison, 2003; Greiner, Grundmann, Krasovec, Pitter, & Wilfert, 2007). However it has not been widely used in developed countries that do not have such a dramatic landscape of violence and politics. In the transition from being a poor country to having comparative wealth, dying from infectious diseases becomes replaced by dying from long term conditions (Wilkinson & Pickett, 2009). This is known as the epidemiological transition. In some senses the area of structural violence has yet to follow that transition, and be applied to the area of chronic illness, which becomes the new context of leading causes of mortality.

It has been argued that the concept of structural violence needs more definition and clarity for in order to be better understood. More needs to be done to connect this concept with theory and empirical methods (Bourgois & Scheper-Hughes, 2004; P. Farmer, 2004). The way in which structural violence has been studied in a context of conflict is influential, as Fassin (2004) describes it, in such settings the past can have omnipresence in the text, but how do we make the connections to daily life (Fassin, 2004). This is echoed by Green (2004), who also indicated that structural violence was lacking in relation to understanding power in daily lives and suggested the analysis doesn't go far enough to gain this understanding (Green, 2004). In many ways this is a challenge arising from what Farmer (2004) calls his description of the ethnographically visible, in that more needs to be done to explore those phenomena less visible. In order to apply structural violence to chronic disease in developed worlds, these challenges must be addressed.

The transnational tale of slavery and debt and turmoil is lost in the vivid poverty, the understanding of which seems to defeat the analyses of journalists and even many anthropologists, focused as we are on the ethnographically visible—what is there in front of us. (Farmer 2004, page 305).

Although structural violence has not been widely applied to developed world settings, Farmer has argued that it has relevance in the US (1994). It has been used as a framework to discuss the intersection of schizophrenia and inequalities (Kelly, 2005), but not formed the basis of empirical research on the topic. Roberts (2009) did use it as an approach to study emotional wellbeing in Northern England. Roberts (2009) offers a personal reflexive account of her observations as a practicing clinician in primary care. This account argues that societal poverty plays out in the daily lives of the patients she worked with, and individualizing fails to connect care in a way that is relevant to the context of people's lives (Roberts, 2009). Marion, Manitowabi, Gzik, McGregor and Corbiere (2011) also drew on structural violence as a framework to analyse diabetes care for indigenous people living in Canada. This research identified the role of social and political barriers, often originating through colonization, that impacted the cultural appropriateness of self-management and care. This was seen to exacerbate the health impact of diabetes, leading to increased risk of complications (Marion et al, 2011).

The limited application of structural violence to the developed world may be for two reasons, one being the lack of the same level of visibility of oppression as provided by a context of such things as civil war, and a lack of methodological development of the concept of structural violence to be applied in developed world settings. However some commentators would suggest that oppression does possess a visibility that is comparable to countries where there have been conflicts. Cathy McCormack (2009) has argued that that the dynamics of poverty in Scotland paralleled the dynamics of oppression in post-apartheid South Africa. Whilst Farmer (2004) contextualises his work in places that often have a context of war with bullets, McCormack (2009) describes the dynamics of oppression in Scotland as the war without bullets, by comparing it to a country where oppression was explicit though apartheid. The methodological challenge though remains, to investigate the 'war without bullets' by considering a range of approaches, such as exploring performance and discourse to understand the social processes that connect structural violence to chronic conditions. By engaging such methods, there is the potential to explore how structural violence exists in the way we all speak, think, exist, care for others and experience illness.

Alongside McCormack's (2009) view, there are also compelling arguments for considering that structural violence in the developed world is mediated through pathophysiological pathways that connect inequalities, stress, depression and heart disease. However in contrast to Farmer's work in Haiti (Farmer, 1999), heart failure in Scotland does not have the same visible physical and political violence that we can draw on to make the case for how structural violence might be expressed in people's lives. Structural violence as an approach has lacked a range of methodologies required to take such an approach out of the dramatic context of civil war or political unrest, and then apply it in relation to chronic illness. Without such a striking contextual backdrop, I argue we need to explore different ways to explore the ideas of structural violence through considering how we make sense of texts, as a main form of data in qualitative health research.

In this thesis I will explore a range approaches that work with considering text at different levels of detail, from the broad role of institutional processes, to the use of discourse, to the analysis of performance as illustrated by specific words or phrases. By doing this I aim to explore the feasibility of a range of perspectives that could be engaged in order to consider structural violence in a developed world context. Others approaches could have been engaged equally, however for the purposes of this thesis, the following perspectives have been identified as one way to explore structural violence. By doing this I will explore how well structural violence can follow the epidemiological transition and develop into being more easily applied in areas that lack the ethnographically visible markers of oppression. These perspectives are broadly defined below, and discussed in more detail in the following sections of this chapter.

- Considering the epidemiological data that reviews the role of social context on disease, including the way in which psychopathological pathways influence health.
- Drawing on institutional ethnography, and its theoretical underpinnings, to relate individual experience to broader social processes, and how we construct knowledge and meaning from texts in ways that pays attention to power.
- Drawing on post-colonial studies to draw on the dynamics of oppression and the role of research in challenging or perpetuating that, with a particular focus on the role of medical research.
- Using Foucault to explore how social processes of power are apparent in discourse and how the system of medical care itself produces fragmented bodies and trajectories of care.

- Exploring how Butler and ideas of performativity explore the use of specific language in illustrating broader social conventions and perpetuating social control

I will now go on to further describe each of these influences and methods in turn.

1.2.5.1 Chronic disease and the biological expression of oppression

Wilkinson and Pickett (2009) argue that social status, social networks and stress all contribute to physical health, including heart disease. Their work makes the case that difficult social conditions lead to emotional and physical responses that can contribute to conditions such as heart disease. Other key studies reflect these findings. The INTERHEART study reviewed the relationship between psychosocial stress and heart disease (Rosengren et al., 2004). Psychosocial stress was associated with an increased risk of myocardial infarction, or heart attack, although the pathophysiological relationship causing this not yet clear (Rosengren, et al., 2004).. The stress associated included self reported stress, such as low sense of control, major life events and external life stressors.

Psychosocial factors, such as negative emotional states, stressors (including job stress) and social factors, (such as social support and social conflict), are risk factors for cardiovascular disease (Everson-Rose, 2005). The earliest psychosocial factors identified as contributing to heart damage included living in poverty, poor housing and poor working conditions, and a comprehensive body of research has associated work stress and increased risk for cardiovascular disease (Everson-Rose, 2005). Chronic exposure to living with discrimination increased the risk of coronary damage for African American women (Lewis et al., 2006).

A further issue to consider is that depression is a risk factor in developing coronary heart disease and in the severity of the disease (Vieweg, et al., 2006; Zellweger, Osterwalder, Langewitz, & Pfisterer, 2004). Depression and coronary heart disease together, may be particularly challenging for clinicians to provide treatment effectively (Vieweg, et al., 2006), and depression increases the risk of mortality for coronary heart disease patients (Barefoot et al., 1996). Having both coronary heart disease and depression together, increases the likelihood a person will die from all causes, as well as from cardiac related deaths (Nabi et al., 2010).

The estimates of prevalence of depression of people with heart failure vary from 20% (Freedland et al., 2003), and as high as 40% depression for those with severe heart failure (Freedland et al., 2003). Over 35% of one sample were identified as depressed, and 13.9% as having major depressive disorder using the Becks Depression Inventory (Jiang et al., 2001). Depression in heart failure patients specifically, increases the risk of a poor prognosis, with increased risks of hospitalisation and mortality (Jiang et al., 2001). One US study with heart failure patients found that there was a higher rate of depressive symptoms in low income patients, and this was even more so with the men in the study (Macabasco-O'Connell, Crawford, Stotts, Stewart & Froelicher, 2010).

There is a tendency to treat depression and coronary heart disease in a causal relationship, although there is much debate about the direction of such a causal relationship (Everson-Rose, 2005), but perhaps one possibility is the presence of shared causal factors of tough lives and hard times, leads to damage on hearts through the relationship between our physical and mental wellbeing. In this sense, the context of peoples lives come to influence their health, and in this way structural violence is biologically expressed, leading to illness and mortality from socioeconomic circumstances.

I think there is a compelling argument for considering that structural violence in the developed world is mediated through pathophysiological pathways that connect inequalities, stress, depression and heart disease. However in contrast to Farmer's work in Haiti (Farmer, 1999), heart failure in Scotland does not have the same visible physical and political violence that we can draw on to make the case for how structural violence might be expressed in people's lives. By taking an approach like structural violence in relation to chronic illness, we can draw on epidemiological data to support this, but need to look to broader methods to explore how such physical health can be an expression of oppression when exploring experience using qualitative approaches.

1.2.5.2 Institutional Ethnography

Qualitative research has been used in a number of ways to explore the dynamics of oppression. Dorothy E Smith (2005) describes how the voice of experience has been essential to understanding the broader dynamics of society, for example in relation to the experience of women in a patriarchal society.

'Speaking or writing experientially has been central in how women have been able to go beyond and outside established discourses as well as to disrupt what seemed at one time the consolidated forms of masculine dominance of intellectual, political, cultural, and domestic life. In this context, giving voice to experience remains a rich source of understanding women's lives, people's lives, inserting knowledge's that rupture those subject to the monologies of institutional discourse and ideology, including the monologies of sociology.' (P124, Smith 2005)

One way to consider the relationship between individual experience and collective experience is the use of institutional ethnography, which draws on how thinking about how work practices can offer insights into what Smith calls ruling relations (1999, 2005). Ruling relations describes the way in which broader social contexts or norms are expressed via institutional practices (Smith, 1999, 2005), and may offer an alternative way to think about the experience of dying with heart failure in relation to the way institutions, such as those providing medical care, respond to the needs of people as they reach the end of life.

A key influence in institutional ethnography is the work of Bakhtin (1981). Bakhtin was a Russian literary philosopher, and his ideas contribute much to how I, as a qualitative researcher, obtain, analyse and retell accounts from participants and about myself. I have drawn on Bakhtin as a way to emphasize the importance of context, including non-verbal context, in the process of working with and analyzing data. When working with qualitative data, I argue we are essentially engaging with, or reflecting different perspectives on, how language is understood, or made sense of. Bakhtin describes language as being dialectically constructed through the context in which the word is from, spoken and used.

As such, 'there are no "neutral" words and forms...; language has been completely taken over, shot through with intentions and accents. For any individual consciousness living in it, language is not an abstract system of normative forms but rather a concrete heteroglot

conception of the world....Each word tastes of the context and contexts in which it has lived its socially charged life; all words and forms are populated by intentions. Contextual overtones (generic, tendentious, individualistic) are inevitable in the word. As a living, socio-ideological concrete thing, as heteroglot opinion, language, for the individual consciousness, lies on the borderline between oneself and the other. The word in language is half someone else's. (Bakhtin, 1981, page 293)

I am particularly struck by the last sentence in the preceding quote, '*The word in language is half someone else's*' (Bakhtin, 1981) and what that means for the way in which we approach working with language, or data. This raises the challenge to consider language as the starting point of analysis, and not the sole focus. Qualitative methods that focus heavily on the transcript as the site of the production of 'data' do so in ways that may actively obscure the half of the language, or sense making, that may not be apparent through what we, or our research participants speak. Language is informed by many layers of context, which may be particularly invisible, in that they may not always be spoken. In conversation with a research participant, they speak as they do because of who they are, and who they perceive the audience, or researcher, to also be. As we speak as researchers, we speak in ways that include the context of all we see and know about that person, even if it is never verbalised.

Monologism, for Bakhtin, describes a condition wherein the matrix of ideological values, signifying practices, and creative impulses which constitute the living reality of language are subordinated to the hegemony of a single, unified consciousness or perspective. Whatever cannot be subsumed under this transcendent consciousness is regarded as extraneous or superfluous. (Gardiner, 1992, page 26)

The idea of the audience, or as Bakhtin may describe, the addressee, that is present in and influences language and conversation, extends to audiences that may not even be physically present. Bakhtin describes the way in which language may also be in conversation with a superaddressee, and this might be the audience of God, medicine, society, science or other overarching narratives that influence what language means, and what language we might choose (Bakhtin, 1981; Holquist, 1990; Mkhize, 2004). Indeed it is the relationship between the utterance of the speaker and the reply of the addressee that is particularly significant (Holquist, 1990), and yet rendered most invisible by transcript orientated analysis approaches. Thinking back to the way professionals try to gain compliance to self-management through placing patients in conversation with medical

research (section 1.2.5), we can see how authority is drawn into exchanges with people with heart failure in ways that might be unspoken, rather relying on the sense of authority of a superaddressee (medical research) as opposed to that of the professional alone.

In contrast Bakhtin also described the idea of the monologic, which is the process of unifying meaning. In some ways the very process of dissecting, describing, prioritising and retelling the meaning we find in interview transcripts is about creating a unitary account for others to engage with. This runs the risk of homogenising the accounts of research participants, but in a way that is influenced by the researcher's own experience, including the superaddressee they are also making meaning in relation to. In health services research, that can mean dominant biomedical approaches influence the manufacture of a unitary account, at the expense of broader meaning. Again this becomes evident in the movement to offer a cogent and unified account of patient experience, based on a lack of diversity of methods or data, as described in 1.2.1.

Dorothy Smith (1999; 2005) draws on Bakhtin in her account of institutional ethnography, additionally she focuses on the influence of dialogism on the activation of text and the relationship between text and the reader. What particularly interests me about Smith's perspective on the activation of texts, is the insights it offers into how meaning can be made, and remade by different audiences, or by the same audience at different times. By text, Smith also means data, and that might be written, observational or visual. She also argues that the activation of texts mostly serves the interests of institutions that such texts may be embedded in (Smith, 2005). In relation to a researcher's interactions with transcript data, information we know or learn can serve to influence our reading of the texts we are working with. That may occur on a number of different levels, be it a theory or approach we become interested in, or information we learn along the way. This raises a warning to researchers about the need to make explicit what influences how we activate text or data, in order to minimize the risk of serving the institutions we are embedded in.

Institutional ethnography argues that the daily lived experiences of people contain an entry point to thinking about how institutions affect and influence our lives, or in other words, individual accounts can illustrate the way in which ruling relations are located in lived experience (Smith, 2005). These ruling relations are not always apparent in the accounts people offer about their daily experiences and the premise of institutional ethnography is to start with peoples' accounts of their lives as a point of inquiry through which to continue

the process of questioning and identifying how lived experience is socially and institutionally mediated (Smith, 2005).

1.2.5.3 Foucault and Post-Colonial Perspectives

Foucault has had an influential impact in relation to how we might understand the development of human sciences, and therefore the development of the ways in which we understand both knowledge and power (Foucault, 1977). The first section of this literature review considered how research can develop norms that come to describe what it is to be a patient with heart failure, and therefore what becomes expected of people as patients, which has relevance to Foucault's analysis of power-knowledge (1977). Hook (2004) argues that Foucault's account of the power-knowledge relationship can also be applied to understanding how people can be objectified and that this objectification is used as a form of discipline over others, mainly through the role of self regulation.

Foucault's (1977) argument about what he describes as the inseparability of power-knowledge, is made by drawing on an analysis of the way in which discipline and punishment has developed historically from being enforced by external authority, to using individualisation of the subject, and self-regulation, against the broader norms or social expectations that knowledge-power influence. In relation to newer forms of punishment, Foucault argues that disciplines such as psychiatry are not neutral forms of knowledge, but are heavily involved in perpetuating self-regulation, and as such lead to compliance with expectations and norms. The process of individualisation is achieved through objectification (Hook, 2004), and I argue here that discourses focusing on symptoms can lead to such an objectification, and self-regulation. The growing qualitative literature of heart failure experience has created a sense of a singular subject of the patient with heart failure (see section 1.2.1), and following that there are different levels of monitoring or surveillance of symptoms as part of what we describe as self-management (see section 1.2.3).

Power works in ways that produce knowledge, that increase the ability to govern individuals (Hook, 2004). The combination of individualisation, objectification and surveillance leads to normalisation, which is a state of being free of irregularities (Hook, 2004). In relation to heart failure this translates to the development of regular, predictable and manageable patients, despite the unpredictability of heart failure itself. This goal of

normalisation is one that is supported by internal self-regulation but reinforced by the role of professional power, such as medical experts (Hook, 2004). Symptoms become a key focus in heart failure, as something to be studied, objectified and self-regulated. In relation to heart failure, the mostly qualitative research on patient experience has led to a sense of what the patient experience is, and as such the norm of the patient living with heart failure becomes established. This then provides the context for self-management, which is primarily the compliance to professional recommendations. However now, the professional has the normalized patient as a guide, and focuses patients on symptoms rather than keeping a view of the patient in the context of their lives.

Hook (2004) provides a useful illustration of how Foucault might be drawn upon to understand certain social processes. Hook argues that the discourses of colonial psychology, psychiatry and medicine were used to measure, describe and create the idea of the African subject. This quest to understand and describe the 'otherness' of African people was deeply immersed in the idea of African people as the non-norm of the European colonisers. Various efforts by psychology, psychiatry and medicine served to objectify African people, and this objectification served only to strengthen the process of colonial power and apartheid (Hook, 2004). African people were considered by colonial psychologists to be unable to be self aware, and in that sense they were beyond even being subjectified, but in contrast, they were without subjectivity at all, a notion which served the colonial forces and gave legitimacy to the oppressive practice of apartheid (Hook, 2004).

The social control exerted in South Africa through apartheid struck a chord with Cathy McCormack in her journey to understand the impact of poverty in Scotland. Whilst Scotland is free of the extreme oppression of Haiti, it is a country that still experiences considerable disadvantage. Cathy McCormack is a community activist who has long argued that being poor in Scotland is much like living in a war without bullets, where oppression drives apartheid between rich and poor, and people die from living in environments that are physically and politically violent (McCormack, 2009). In her work she draws parallels between the struggles in South Africa and the struggles of deprived communities in Scotland. For McCormack, oppression is expressed through large damp housing estates on the edges of Scottish cities, where violence and despair dominate. McCormack (2009) felt that the processes of oppression in apartheid resonated with the structural violence she describes in her own community in Scotland. Cathy McCormack's personal story of struggle, along with her analysis of the violence and oppression in her community, has influenced how I make sense of the extent of poverty and exclusion in Scottish society

(2009). Perhaps as a non-Scottish person, although I had lived in Scotland for many years, my initial shock at the scale of socioeconomic inequalities in Scotland has remained with me, and forms my own historical backdrop for my interest in understanding the processes that unfold between oppression and biology.

Tuhiwai Smith (1999) also writes about the way in which research with indigenous people can reflect dominant ideas of colonisation. She convincingly argues that indigenous people were researched through colonisation and conceptualised as not fully human, and in need of being studied, classified and understood, and those classifications informed relations between imperial powers and indigenous people (Tuhiwai Smith, 1999). In many ways, so called objective research, that in fact reflects deeply engrained and privileged assumptions, led to what Tuhiwai Smith (1999) describes as an 'othering' of indigenous people. This 'othering' has consequences for those that are studied, and those consequences privilege dominant groups that benefit from the underlying assumptions. Tuhiwai Smith (1999) gives the example of how Australian Aborigines were hunted and killed until the early nineteen hundreds as the process of 'othering' led to the categorisation of Aboriginal people as non-human. In more recent times Butchart (Butchart, 1996; Butchart, 1997) gives examples of how medical research played a significant role in supporting the oppressive regime of apartheid in South Africa. The challenge that exists in my work is to ask the question: when we conduct health related research, are we 'othering' those that live and die from chronic medical conditions, people who tend to be those who are the most disadvantaged in our own communities, and how does that provide a foundation for a structural violence we all participate in.

The control of the spread of infectious disease, particularly in oppressive states, can lead to medical control venturing into social control, through informing and regulating social contact between people, as Butchart (1997) argues was also the case in South Africa. Butchart explores how research was involved in the understanding and controlling of infectious disease from 1900 to 1950, in a way that was reflective of the oppressive practices of apartheid.

The device of perceiving bacterial exchange between the diseased and the healthy as the means by which tuberculosis and other diseases were spread, these practices comprised an extended medical gaze that moved surveillance from the inside of the body to its exterior, into the spaces of social contact between the sick and the well. (Butchart, 1996, page 189)

In the later part of this 1900 – 1950 period described by Butchart (1996) the focus of surveillance of African migrant workers became tuberculosis. The objectifying categorisations about workers that were already developed supported further examination of workers, mostly in terms of their racial deficits leading to susceptibility to infectious disease. The infectious disease model led the areas of scrutiny, objectification and surveillance outside of the body, to include the social world also.

But, no matter how impersonal, whenever it occurs the medical examination always renders those it isolates for inspection forever subject to the knowledge that they have been observed, and to the knowledge that they cannot know what about them has been seen, heard and recorded, or how such information may be used. It is in this face of the medical examination as the silent induction of its human objects into the domain of ceaseless surveillance that remains hidden by those who would resist its powers by challenging whatever components of repressive force it may be blended with. Further, it is precisely such resistance that intensifies the power of the medical gaze to individuate and discipline the body it invents. (Butchart, 1996, page 193)

The point that Butchart (1996) so clearly makes is that the perpetuation of discourses that dominate and oppress is fluid. He illustrates how Foucault's idea of power-knowledge develops dynamically, with discourse creating and perpetuating further discourse that reflects the broader social, historical and political context, which in this case was apartheid. The disciplinary power becomes perpetuated institutionally and acts upon both those that are oppressed (the migrant workers) and those that oppress (the medical authorities themselves).

Armstrong (1987) has reflected on the same process of scrutiny and surveillance in relation to the changing nature of dying. Through the early 19th century, death changed from being a community matter, to becoming regulated by medicine and public authorities (Armstrong, 1987). Where the matter of death had been once the realm of neighbours and families, death became something that had to be registered by law, accountable to the public and monitored by medicine (Armstrong, 1987). The routines of investigation, examination and analysis on the part of medicine, transformed dying to being a public and medical matter (Armstrong, 1987). The regulation of dying became a way to attempt to monitor populations, as a form of surveillance (Armstrong, 1987). Armstrong (1987),

drawing on Foucault, illustrates these processes as establishing new biological discourses around dying, and how the associated disciplinary power lead to the medicalisation of dying and the silencing of the dying themselves. Here I argue that applying such an analysis to the experience of people with heart failure will help explore the processes that may be integral to how structural violence is perpetuated in a chronic disease context.

1.2.5.4 Performativity

Butler (1999, 2000, 2005) offers a way to think on the issue of subjectivity in the context of how it relates to broader social understandings or norms, and draws on the idea of utterances to illustrate this connection. I am drawn to Butler (1999, 2000, 2005) as a way to explore broader context through taking a much closer examination on the detailed and specific use of language. For Butler (1999, 2000, 2005) performativity is an illustration of how societal norms and expectations attempt to achieve social control (Salazar-Sutil, 2008). Butler's work focuses primarily on issues around gender, and she would consider that we are all, always performing in ways that are either consistent with or resist broader norms (2000, 2005). There are many different utterances that support this, and Butler (2000) gives examples of specific statements, such as 'it's a girl' announced at a birth, or 'I do' announced at a marriage, as being examples of how both announcements evoke a broad range of expectations about roles and behaviour. In doing this she connects the idea of how individuals are responding, to broader social processes. Additionally, Butler's (2000) approach illustrates something of how norms are created, maintained and resisted, although such an approach has not been applied to the area of heart failure previously.

Discursive ideas of performance are described by Butler (Butler, 2000), drawing on J L Austin's (1962) idea of performative utterances, which are authoritative acts of speech, and have binding power. Examples of this could include the idea of the marriage, which both Butler and Austin draw on, both in relation to 'I do' and 'I now pronounce you'. These are examples where the utterance is more than a description, it is action, it describes something we do, not only as we say it, but also beyond the act of speaking, it brings things into being. Performative utterances are described as both repetitive and able to be reinforced by authority, and through this they build a range of binding conventions, which in turn enforce expectations about norms (Butler, 2000).

Butler (2000, 2005) makes a compelling analysis of the way in which gender is performed. In relation to gender, norms are evoked with utterances like, 'it's a girl' as a baby is being born, in that it means much more than the words, but describes a broad range of knowledge and norms that produce a binding meaning to that utterance, and give it authority (Butler, 2000). In terms of aspiring to live up to the norm, the baby girl will never grow to be all that it means to be a girl and a woman according to the norms evoked by such utterances, but will always be either conforming to, or resisting, those norms. Butler (2000) argues it is the citations, or speech that we have, that highlights the role of norms in creating the viable subject. What we utter and perform, are not making the 'truth' of gender, but can illustrate understandings that are more broadly held about what is compulsory for us to either perform or negotiate. Butler (2000) describes norms as having an inefficacy, which is why small repeated utterances are needed to cite norms, and she describes subversion of norms as '*working the weakness in the norm*' (page 114). For Butler, gendered behaviour is not something that is inherent within us, but comes from conformity with, or resistance against gendered norms that surround us.

Drawing on Butler's (2000, 2005) analysis, I am interested in the performative aspects of living with heart failure. In particular, Butler's (2000) approach illustrates something of how norms are created, maintained and resisted. This is of interest to me in relation to exploring ways to conduct research that considers broader contexts. In living with heart failure then, what does it mean to learn the norms of 'the patient', and indeed what does it mean to have 'heart failure' itself? If this can illustrate how performativity starts to become an act of social control (Salazar-Sutil, 2008), this can offer further insights into how structural violence becomes expressed in all our daily practices. In this thesis I will explore the use of performativity in relation to how it contributes to the qualitative methods used to explore heart failure, and how it may further our learning about what it means to be a patient living with heart failure.

1.2.5.5 Relationship between theoretical perspectives

We need the power of modern critical theories of how meaning and bodies get made, not in order to deny meanings and bodies, but in order to build meanings and bodies that have a chance for life. (Haraway, 1988, page 187)

Each of these perspectives interacts, sometimes contrast and sometimes complement each other. In some ways they represent different levels of interaction with data or texts, providing a broad range of methods for exploring how different methods can assist in this challenge of applying the ideas of structural violence to a developed world setting. Engaging these different approaches allows exploration of how to explicate the idea of structural violence in different ways, rather than seeking the ideal way to do so.

Institutional ethnography, and its theoretical underpinnings, provide opportunities to relate individual experience to broader social processes, and how we construct knowledge and meaning from texts in ways that pays attention to power. Smith (2005) reclaims the utility of experience, and contrasts herself to Butler (1999), who she critiques for dismissing the importance of experience due to its constructed nature. However I believe they have identified the same issue with dealing with experience, and that is that language, and text, are shaped with the influence of norms, expectations, institutions, society, but for Smith that is a resource for locating the impact of broader social conditions in experience, and using that resource, certain claims or understandings about experience can be explored. For Butler that is not so much the case, as those contaminants illustrate the limitations of knowing. Exploring how Butler and ideas of performativity explore the use of specific language in illustrating broader social conventions and perpetuating social control adds another perspective to illustrating how oppression becomes integrate into daily experience.

Drawing on post-colonial studies, particularly in combination with Foucault, may offer ways to explore the dynamics of oppression and the role of research in challenging or perpetuating that. In particular there is a focus on how social processes of power are apparent in discourse. I suggest that it is worthwhile to complement Foucault's approach by drawing on the work of Bakhtin (Bakhtin, 1981; Holquist, 1990). In contrast to Foucault, by drawing on Bakhtin, I would argue there is greater potential to consider what is not always explicitly apparent in discourse, but influential to how discourse is created and used.

Regardless of how accurately a person understood their diagnosis and prognosis of heart failure, there was a prevailing sense that science and medicine spoke with an authority about the heart, that evoked Bakhtin's notion of the superaddressee (Holquist, 1990; Hook, 2004; Smith, 1999). Foucault sees discourse as something that individuals participate in, and therefore also reproduce or perpetuate (1977). In contrast, Bakhtin describes the role of dialogism, which draws on the way in which speech, or utterance, has an audience. That audience includes the addressee, or the intended listener such as me as the researcher, but also the superaddressee, being a broader audience, such as science, God, or medicine (Holquist, 1990; Hook, 2004).

In this work I am to draw on each of these perspectives with the goal of elaborating upon how structural violence can more subtly illustrate the biological expression of violence in relation to heart failure in Scotland.

1.3 Heart failure and structural violence

Those working in the health professions are as concerned with prevention as with healing. So doctors must involve themselves with the conditions that foster violence. These conditions include the social forces that influence individuals and societies to initiate or tolerate violent acts. It is a trivial truth to say that doctors are not politicians. But medicine and its institutions cannot escape politics. (Horton, 2001 page 1472)

There are potentially many benefits to bringing an analysis of structural violence into the understanding of heart failure. As Horton (2001) eloquently describes in the quote above, violence must be understood through furthering our analysis of social forces. However Horton saw the importance of this in relation to the developing world, and here I argue such an analysis needs to also happen in relation to western world settings, where poverty continues to perpetuate a violence in relation to its citizens.

In Scotland socioeconomic disadvantage leads to much higher levels of mortality from heart disease, the worst example being in relation to people under the age of 75. While deaths from coronary heart disease are decreasing overall, they are decreasing less quickly for those in the most deprived population (Scottish Government, 2008). Indeed there is some indication that life expectancy appears to even be decreasing in some of the most deprived

areas in Scotland (Scottish Government, 2008). The Equally Well ministerial taskforce report states:

Deprived populations have considerably higher levels of mortality from coronary heart disease (CHD). This relationship is evident for all ages, but is strongest in those aged under 75 years for whom mortality rates from CHD in the 10% most deprived areas are 3.5 times higher than in the 10% least deprived areas (Scottish Government, 2008).

Epidemiological studies show that heart failure is very much an inequality condition. Heart failure is associated with deprivation (McAlister et al., 2004), and is also associated with disproportionately ill health, mentally (Freedland et al., 2003; Vieweg et al., 2006) and physically (Jiang et al., 2001; Nabi et al., 2010). One US study with heart failure patients found that there was a higher rate of depressive symptoms in low income patients, and this was even more so with the men in the study (Macabasco-O'Connell et al, 2010).

Deprivation leads to patients being 44% more likely to develop heart failure and less likely to see their GP regularly (McAlister et al., 2004). The reasons for a lack of regular review is unclear, but the authors suggest it could be due to greater fatalistic attitudes in this group, greater reliance upon emergency care provision or a lack of regular follow ups being offered (McAlister et al., 2004). Until research on patient experience of living with heart failure starts to address the role of deprivation and inequalities, serious challenges remain in providing the care or services that people with heart failure that can start to address the gap in being diagnosed with heart failure and the length of time till death.

Social epidemiological research, such as that by McAlister et al (2004), supports the assertion by McCormack (2009) that there is a 'war without bullets' where social inequalities lead to isolation and increased mortality. This also illustrates the potential gains in considering structural violence and engaging methods that can help apply this approach to the developed world. Chronic disease, such as heart failure, may be what infectious disease means to the developing world, which to Farmer (1994, 1999, 2004) is a biological expression of oppression. However more subtle methods are required to explore this in the absence of the ethnographically visible conflicts which are a feature of the settings of Farmer's work (1994, 1999, 2004).

As outlined in the first section of this literature review, there has been a heavy reliance on qualitative methods in researching heart failure that have taken an individualizing perspective, leading to calls to broaden research to include more social context for people

with heart failure (Jeon et al, 2010). In some ways our desire to describe, categorize and cogently label the experience of people with diseases has a quality reminiscent of colonial methods described by Butchart (1996, 1997) Tuhiwai Smith (1999), which lead to an 'othering' of indigenous people. In comparison, people with heart failure become othered into the role of patients. The growing consensus in qualitative literature about patient experience leads to the establishment of the normalized patient, from which care can be planned and expectations of all patients formed. However, this normalized patient reflects a very limited range of patients, or qualitative methods, on which these ideas are based. A structural violence perspective would suggest that such a process is one that has potential to serve the interests of dominant ideologies, and is part of the 'social machinery of oppression' that is based on individualizing experience in ways that reflect social order (Farmer 1994, page 307).

If the potential exists for the people with heart failure to be othered through establishing what it means to be a patient, this reflects how the dominant medical ideologies become expressed into shaping patient experience. The importance of this context is further affirmed in the self-management literature, where much non-compliance is argued to be influenced by broader socioeconomic factors ((Macabasco-O'Connell et al, 2008).). The processes involved in shaping the experiences of people living with heart failure can be explored in a number of ways, including through considering Foucaudian perspectives on discourse (1997). This is one area of heart failure literature where there has been some research published, particularly in relation to the discourses used to reinforce authority in negotiations between patients and professionals (Sanders et al, 2008; Sanders & Harrison, 2008). A further perspective that will be explored is that of performativity (Butler 1999, 2000, 2005), where the norms, which have been established in relation to heart failure through qualitative research and reviews, are resisted or performed. Butlter would argue that the norms are reflections of broader social values, of which there are authoritative utterances that draw these broader values into play (1999, 2000, 2005). Using this approach may offer insights into how social processes operate, which contribute to structural violence in relation to heart failure.

Bringing a structural violence perspective to the area of heart failure, and a challenging the area of structural violence to be better applied to chronic disease, is novel and innovative work. Such a combination will lead to new areas of exploration for both structural violence and offer an innovative contribution to our understanding of heart failure.

1.4 Research Aims

This thesis has two main aims, which focus on exploring the experience of heart failure as a way to see how context plays out in the lives of individuals living with heart failure. The first aim focuses on the methodological issues of the relationship between experience and context. The second aim explores how this unfolds in relation to living with heart failure, with a particular focus on the role of structural violence as one perspective that can illuminate this relationship.

- To consider the role of qualitative research methods in contributing to, or addressing, my sense of disconnect between how to explore experience and subjectivity, whilst retaining the importance of surrounding social context.
- To explore the experiences of people as they live with and die from heart failure in ways that situates their accounts in the broader context of their lives and the system of medical care of which they become a part.

2 Methods

Knowledge is different for the powerful than it is for the oppressed. (Parker, 2005, page 8)

This thesis is based on research undertaken when I was appointed as a research fellow on a project funded by the British Heart Foundation and the Department of Health (Boyd, et al., 2009). To that extent the project already was set up, and I undertook the fieldwork and analysis. However it was my experience of being part of that process that led to the development of this thesis, which both builds on and is distinct from the original project. The original project had aims that were specific to exploring the different needs of patients, carers and professionals and their experiences across different models of care. This thesis extends the analysis by exploring different approaches to understanding experience through taking different perspectives on what it is like to be living with and dying from heart failure, including considering the research process itself. Here I describe the background of the original study, the participants in the research, provide a critique of qualitative methods often used in health related research, and go on to describe my own approach and methods used. Finally this chapter will discuss the ethical issues involved in conducting this research.

2.1 Background to the Original Study

The data from this project arises from a project called '*Patients', carers' and professionals' experiences of diagnosis, treatment and end-of-life care in heart failure: A prospective qualitative interview study*' (Boyd, et al., 2009), on which I was the lead researcher. The aims of that longitudinal study were to compare different models of care for people with advanced heart failure through reflecting on the experiences of patients, carers and professionals across those models of care. 30 people living with advanced heart failure (along with their carers and professionals) were recruited into the study, and semi-structured interviews were conducted, leading to a thematic analysis of transcripts, drawing on grounded theory (Charmaz, 1995; Glaser, 1967) to guide the analysis process.

The project had set goals, questions and an agenda mainly driven by the research team involved in designing the project and participating on the steering group providing guidance to the research process. As the lead researcher I conducted the research, and in that process developed my own questions and lines of analysis which form part of this thesis. The research was a palliative care project, and the people recruited were often very unwell, and often not aware they had the diagnosis of heart failure. This led to a participant-centred, or participant-led, approach to interviewing. Whilst the data generated addressed the project team concerns, it also generated much more learning beyond the focused aims of the original research. That data and learning forms the basis of this thesis.

The original study aims were:

1. To explore the perspectives of patients and their informal carers concerning their holistic needs and the services available to them at key stages of the heart failure illness trajectory
2. To elicit the views of key professionals providing treatment and care for people with advanced heart failure
3. To propose needs-led models of treatment and palliative care for patients with advanced heart failure that might be appropriate for national use, considering in particular the interface between active treatment and palliative care, the role of heart failure nurse specialists, primary care team members, and other mechanisms of community support.

The original study's research questions were as follows:

- a) What do patients with advanced heart failure and their carers perceive as their main needs from diagnosis to death and in bereavement, and how do they manage the illness?
- b) To what extent do patients and carers understand the diagnosis of heart failure, its treatment and prognosis?
- c) How do professionals address patients' and carers' information needs in hospital and the community?
- d) What services are provided in hospital and the community for patients with advanced heart failure and their carers at different stages of the illness and how might these be improved?

- e) What models of care would meet the needs of people with end-stage heart failure and their carers more effectively?

The two and a half year long study commenced in April 2004. The research was conducted in Lothian, which included Edinburgh and the surrounding areas in Scotland. At the time of the research, Lothian had a multidisciplinary heart failure network, heart failure nurse specialist service and a volunteer support service. During the research I also became involved in helping to set up a patient heart failure user forum, which was set up as a way to offer a space for heart failure patients to come together for information and support.

2.2 Participants

Participants were recruited through contacts with consultant cardiologists, heart failure nurse specialists, consultant geriatricians and general practitioners. A wide range of participants were sought, both to reflect a range of models of care and a diverse range of participants in relation to age, gender and location. Participants nominated a carer, if they had one, and a key health care professional to also be approached to see if they were prepared to take part in interviews. Each participant, their carer and professional were interviewed three times over a six month period. If a participant died during that time, bereavement interviews were carried out with the carer and professional where possible. The interviews were at recruitment, 4 – 6 weeks later and 4 – 6 months later. This spacing was chosen partly because many participants were recruited following in-patient admissions, and the first interview might be during an admission. The second visit was timed to allow time for the participant to be visited post discharge, but close enough to their admission to reflect on the experience of their admission and discharge. The third and final visit was placed 4 – 6 months later, to allow a follow up with a reasonable amount of time for care to be established, and for a wider variety of experiences in living with heart failure to have occurred.

Interviews with patients and carers were mostly conducted individually, although some participants chose to be interviewed together. There was a comprehensive interview schedule (see Appendix A) however due to ethical requirements to not mention heart failure, and the limited health of many participants, the interviews tended to be quite unstructured and led by the person with heart failure. Health issues such as breathlessness made it challenging for some people to talk for long periods of time, so the interviews were conducted at the participant's pace. Interviews ranged in length from 20 minutes to two hours, although typically lasted around 1 hour. Interviews with professionals tended to be much shorter, generally lasting around 30 minutes.

I conducted this research as a white New Zealand woman, living in Scotland with my female partner and our two daughters. I considered Scotland my home as I had lived there a long time, however I was notably different to my participants, in that I was much younger, and not Scottish. I really did not know much about heart failure when I started the research, although I had a strong history of heart problems in my immediate, and extended family. Participants often asked me questions about why I was living in Scotland, and I was usually quite private in my responses, preferring not to bring attention to other ways in which I was different to my participants, such as in relation to my sexuality.

From the original study of 30 participants I have decided to focus on a smaller number of 20 people with heart failure. This is mainly because this subset reflects those participants that were interviewed by me exclusively, whereas the remaining 10 had some or all interviews conducted by a different researcher.

For the 20 people with heart failure included in this study, 48 interviews were conducted with people with heart failure, 38 interviews with their nominated carers and an additional 36 interviews with professionals. The professionals interviewed included heart failure nurses, GP's, Geriatricians, nurses, hospice nurses, a volunteer and a district nurse. Overall a total of 122 interviews were conducted for this thesis. Of the 20 participants, six died during the study. The ages of participants ranged from 64 to 87, and there were ten men and ten women, although I should note that whilst I had sampled to ensure variety on a range of criteria (particularly in relation to care provision), this exact gender split was not deliberately obtained. All interviews were recorded and fully transcribed for analysis. A full description of each individual in this project can be found in Appendix B. All names used in this thesis are pseudonyms.

Of the 20 participants included in this thesis, 10 were recruited through the Heart Failure Nurse Specialist service. I knew that 9 of those 10 knew their diagnosis of heart failure (one was informed between my first and second interview with her). There was one participant who had a heart failure nurse specialist, but I had not established if she knew her diagnosis due to her very poor health when I interviewed her (and she subsequently died not long after our first interview). Only two additional people, who did not have a heart failure nurse, appeared to know their diagnosis of heart failure, although I cannot be certain that the remaining 8 participants who did not have a heart failure nurse, did not know their diagnosis.

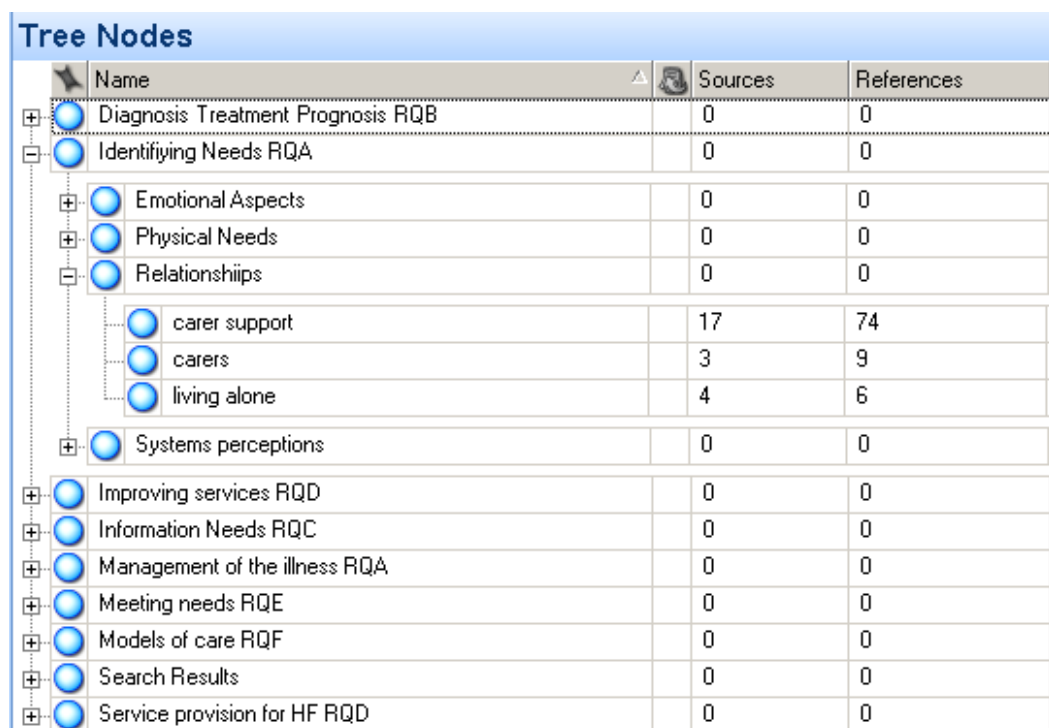
I conducted and reported on a thematic analysis of the full data set of 30 for the main study, which was reported in relation to the original project research aims and is published elsewhere (Boyd, et al., 2009). Here I am going to try to describe the methods used in this thesis by offering a critique of qualitative analysis methods and then describing the different approach that I took.

Each participant had their 'depcat' code noted (NHS Lothian, 2003). This is a code that was used at that time to make an approximation of deprivation in Scotland, although now it would be more commonplace to use the Scottish Index of Multiple Deprivation to estimate deprivation. In this research project we followed the NHS Lothian approach of grouping depcat scores as follows: depcat 1-2: affluent; depcat 3-4: intermediate; depcat 5: deprived; and depcat 6-7: very deprived. It was estimated that across Lothian 24% of the general population had a score of 5 or above (NHS Lothian, 2003). In this sample of 20, 40% (n = 8) had a score of 5 or above. This indicates that this sample of participants were more likely to be living in deprivation than a sample of the general population. However as heart failure is more likely to develop in, and progress faster for people living in deprivation (McAlister et al., 2004), this level of deprivation might be expected in this sample.

2.3 Secondary Data Analysis

This thesis represents a secondary analysis of data in many ways. I should point out that I did not explicitly ask people to reflect on if their material circumstances or mental health would influence to the manner in which they would die. In this research it would have been challenging to do so, given the ethical restrictions around talking about dying. What this study has done however, is revisit the initial data, and build on the initial data analysis to ask further question about the context in which people live and die with heart failure, with a particular interest in further exploring an analysis of structural violence.

The initial data was heavily coded and organised around the research aims, including consideration of the role of different services and identification of needs. Figure 1 shows the 'top level' node structure in the initial analysis, with detail of sub-level coding shown for the node concerning 'relationships'. Top level coding does not illustrate the extent of coding, as coding was applied at the sub-node level.



| | Name | Sources | References |
|---|-----------------------------------|---------|------------|
| + | Diagnosis Treatment Prognosis RQB | 0 | 0 |
| - | Identifying Needs RQA | 0 | 0 |
| + | Emotional Aspects | 0 | 0 |
| + | Physical Needs | 0 | 0 |
| - | Relationships | 0 | 0 |
| | carer support | 17 | 74 |
| | carers | 3 | 9 |
| | living alone | 4 | 6 |
| + | Systems perceptions | 0 | 0 |
| + | Improving services RQD | 0 | 0 |
| + | Information Needs RQC | 0 | 0 |
| + | Management of the illness RQA | 0 | 0 |
| + | Meeting needs RQE | 0 | 0 |
| + | Models of care RQF | 0 | 0 |
| + | Search Results | 0 | 0 |
| + | Service provision for HF RQD | 0 | 0 |

Figure 1: Outline of top level coding structure in initial analysis with a detail view of the 'relationships' node.

The initial analysis provided a comprehensive basis for this study's subsequent continued coding and analysis. This is apparent in the restructuring of the top level coding, and in Figure 2, top-level nodes are shown, with the 'relationships' node expanded to provide an example of further coding and analysis conducted.

| Tree Nodes | | | | |
|------------|--------------------------------|--|---------|------------|
| | Name | | Sources | References |
| - | B secondary analysis | | 0 | 0 |
| + | Accounts of daily life with HF | | 0 | 0 |
| + | Medicalisation of the Heart | | 0 | 0 |
| - | Relationships and Power | | 0 | 0 |
| + | Assessing information ne | | 0 | 0 |
| + | Communication | | 0 | 0 |
| | informal support | | 14 | 32 |
| + | Issues around help | | 0 | 0 |
| | loss | | 7 | 9 |
| | monitoring of condition | | 14 | 24 |
| | reassurance | | 2 | 3 |
| - | Relationships | | 0 | 0 |
| | carer support | | 17 | 74 |
| | carers | | 3 | 9 |
| | continuity of relations | | 4 | 7 |
| | dependence | | 10 | 17 |
| | living alone | | 4 | 6 |
| | negotiating carer rela | | 18 | 45 |
| | relationship between | | 6 | 12 |
| | relationship with prof | | 18 | 49 |
| | state of current services | | 13 | 23 |
| + | Types of information | | 0 | 0 |
| | views on quality of care | | 12 | 30 |
| + | Unpredictable dying | | 0 | 0 |

Figure 2: Secondary analysis top-level coding and 'relationships' node.

Data and existing themes were systematically read and reread in light of the thesis research questions, evolving analysis and additional data which provided input relating to the broader context. Such additional data included texts, such as patient information, patient education DVD's, more comprehensive field notes, observations and socioeconomic context. Data for each participant was linked through using the 'cases' facility in NVivo,

which allows for data to be collected into a connected set of data in order to facilitate data linkage to key demographic or quantitative data. Cases were created for participants, and also created for roles. This allowed for reviewing of data in relation to key participant attributes, including role of patient, carer or professional. Additionally cases were created for each patient, integrating all relevant data for that patient and linking it, allowing for review and analysis within and between cases. The result of this additional analysis was a new emerging analysis, which is the foundation for this thesis, consisting of the identification of themes, key illustrative texts and discourses.

A secondly aim of this thesis was to engage in a debate about how different methods might further facilitate consideration of broader context in relation to living with and dying from heart failure. Table 1 provides a summary of the differences between the original study and this thesis. It should be noted that a subset of participants were selected primarily because I had collected the entire data set for each of these individuals, while another researcher had also collected data for the remaining ten. The subset reflects my desire to work with the data I had collected personally, allowing for consideration of contextual data and reflections from my own experience of conducting the field work.

There are strengths and weaknesses to this secondary analysis. The strengths include the way in which this thesis adds further exploration to the original analysis, providing insights into context, which may further enhance the learning from this work. There is also strength in providing a space through which additional data could be considered in a way that was theoretically based and methodologically systematic. In examining the structural violence framework, the goal included exploring whether oppressive practices are not imposed, or collectivised, rather to explore if they are evident in all experiences or practices, and become embedded in daily life and routine to the delivery of care.

Table 1: Summary of original study and secondary analysis conducted for this thesis.

| | Original Study | Secondary Analysis |
|-------------------|---|---|
| Study aims | <p>1 To explore the perspectives of patients and their informal carers concerning their holistic needs and the services available to them at key stages of the heart failure illness trajectory</p> <p>2 To elicit the views of key professionals providing treatment and care for people with advanced heart failure</p> <p>3 To propose needs-led models of treatment and palliative care for patients with advanced heart failure that might be appropriate for national use, considering in particular the interface between active treatment and palliative care, the role of heart failure nurse specialists, primary care team members, and other mechanisms of community support.</p> | <p>1 To consider the role of qualitative research methods in contributing to, or addressing, my sense of disconnect between accounts of how experience and subjectivity, and surrounding social context, particularly in relation in socioeconomic circumstances.</p> <p>2 To explore the experiences of people as they live with and die from heart failure in ways that situates their accounts in the broader context of their lives and medical care.</p> |
| Design | Prospective longitudinal study, with baseline, 4-6 week, and 4-6 month follow up interviews. | Prospective longitudinal study, with baseline, 4-6 week, and 4-6 month follow up interviews. |
| Sample | 30 people with heart failure, their carers and professionals associated with their care. | 20 people with heart failure, their carer and professionals associated with their care. |
| Data | 162 interviews | 122 interviews, ethnographic field notes, personal reflexive account, mixed media materials published during the study, and/or provided to participants by local services |
| Analysis | Thematic analysis of interview transcripts | Thematic analysis of interview transcripts, analysis of illustrative texts demonstrating performative concepts, text analysis of documents, analysis of discourse from a foucauldian perspective, reflecting on use of methods. |

There are weaknesses also. This thesis is limited by mainly using the data it critiques, in that while an over reliance on interview transcripts can encourage over individualizing of experience, this thesis also relies on such data. If the emphasis on structural violence had been integral to the study design, this would have influenced the research design and the methods used throughout. In particular, if it had been engaged in the study design, it might have been very useful to draw on institutional ethnography (Smith, 1999, 2005) as a main method of data enquiry. There are excellent examples of how this can be engaged as a method for working alongside and with participants in joint enquiry, one such example being the outstanding work of Ellen Pence in conducting 'safety audits' in communities attempting to reduce violence against woman (Pence, 2001). This work shows a very promising application of the institutional ethnographic methodology. However, even institutional ethnography had its origins in a secondary data analysis (1999), which does illustrate that while not ideal, it is possible to bring new approaches to the process of interrogating data from new perspectives, although with limitations.

2.4 Critique of Qualitative Analysis Methods

Research has played a role in building the foundation of knowledge, which has a significant impact on how we have come to understand our world and the people in it. There are many examples of research generating knowledge in ways that reflect dominant social views of the time, or being used in ways that perpetuate historical conditions. In 1839 Samuel Morton made a contribution to the field of racial categorisation by measuring skull capacities of different racial groups through using seed (Morton, 1839). He would fill the skull with seed, and then compare the volume collected by racial groups. Morton found that skull sizes differed by racial group, and that Caucasian skulls measured as the largest skull size, accounting he alleged for differences in intelligence. Future examination of Morton's data revealed that he was so influenced by his unconscious assumptions and beliefs, that his calculations were incorrect. Re-examination of his raw data did not in fact support Morton's hypothesis at all. However Gould (1981) found that Morton showed no signs of consciously distorting his research, and concluded that it was Morton's views and assumptions, which were shaped by the historical context of when he conducted his work, that had powerfully influenced his research process, and his use of so called objective methods.

I detect no sign of fraud or conscious manipulation. Morton made no attempt to cover his tracks and I must presume that he was unaware he had left them. He explained all his procedures and published all his raw data. All I can discern is an a priori conviction about racial thinking so powerful that it directed his tabulations along preestablished lines. Yes Morton was widely hailed as the objectivist of his age, the man who would rescue American science from the mire of unsupported speculation. (Gould, 1981, page 20)

Of course in qualitative research we are not measuring skulls, but we can learn from Morton (1839) that we bring to our work our own sets of assumptions, politics, philosophical positions and theories, and that influences what we research, how we research it and what we find. The influence of philosophical, political or theoretical positions was never more evident than in the work conducted by Morton (1839), however it is the clarity of hindsight onto a different historical time, that makes Morton's bias seem so obvious. As such, we can be warned that our work now, may be equally exposed in time to be a reflection of our views, assumptions, politics and historical context, regardless of attempts to achieve objectivity.

A range of qualitative methods have aspired to achieve a degree of the objectivity and rigour that undoubtedly motivated Morton. This has led to the rise of methods that offer systematic processes of working with data that offer rigour, such as grounded theory (Glaser, 1967) and particular phenomenological approaches, such as interpretive phenomenological analysis (Smith, 1997). Whilst there have been attempts to extend grounded theory (Charmaz, 1995; Clarke, 2003; Willig, 2001), and there are other approaches to phenomenology that may be more contextualising (Van Manen, 1990), both approaches have a particularly heavy focus on individual accounts, as captured through transcribed recordings of interviews. These transcripts are then subjected to systematic processes, and those processes become the focus of research efforts. Finding the way in which ideas are shared by groups or participants (Glaser, 1967) can become a focus of such approaches, and this can lead to researchers weighting meaning by the frequency of accounts, rather than the nature and context of ideas. Narrative analysis (Frank, 1995; Reissman, 1993) also has some aspects of such individualising, although it may have more potential for considering context through exploring the relationships between ideas, and between research people. The effect runs the risk of being the same as Morton's

seeds, the transcript is taken as the objective data that somehow transcends the position of the researcher in conducting or analysing the work, and the broader context is quickly obscured by the focus on tangible data. The cost of such approaches is the consideration of any other information that may be regarded as data, including data used to contextualise the focus of investigation. Additionally, such a focus on single data sources, and processes of analysis, can obscure how the status of the researcher's claims, are also a reflection of the researcher's point of view, and how that is part of the external context of sense making in data analysis. Ian Parker commented on this effect in relation to IPA:

Reduction to the individual – which is a way of viewing narrative that separates figure from ground so that we concentrate only on what we imagine to be the 'inside' perspective. This means we lose sight of how what is 'inside' is dependant on what is 'outside' the individual as the context for narrative to make sense to us. (Parker, 2005, page 74)

The increasing use of qualitative methods has perhaps led to the rise of these attempts to address issues of rigour (Barbour, 2001). The focus on rigour however, can become expressed as a range of technical approaches to aspects of method (for example the use of triangulation, or the application of grounded theory), which may not be able to realistically address issues of rigour, but are at times expressed as authoritative guidelines to researchers (Barbour, 2001). Alternatively, focusing on the principles or values of qualitative research, and analysing how well research adheres to those values (for example, that of diversity of views), may offer a more constructive approach to understanding rigour (Barbour, 2001). The undue influence of checklists that intend to address the rigour of qualitative research, can actually encourage a sort of '*technical essentialism*' (Barbour, 2003, page 1020). Methods such as Framework Analysis (Ritchie & Spencer, 1994) , could be considered examples of approaches that follow '*technical essentialism*' (Barbour, 2003). There is a need to examine more closely the role of theoretical positions used by the researcher, alongside the methods used, as they are intricately connected and influential on the process of qualitative research (Barbour, 1998). This is particularly important when combining methods, or approaches in qualitative work.

Grounded theory can be used in ways that evoke this '*technical essentialism*' also (Barbour, 2003). Barbour (2003) argues that grounded theory used in this way, separates analysis from theory, and excuses the researcher from engaging with the broader theoretical context of their work. Barbour (2003) goes on to argue that the role of the agency of the researcher is also severed from research that has a '*technical essentialism*' approach, removing the impact of the researcher themselves on the data collection and analysis. As I reflected in Chapter 1, I have myself experienced the reduction of my agency in conducting research, which led to an increased reliance on '*technical essentialism*' in my own work. In my view these issues are replicated on an ever greater scale in the systematic reviewing of many studies that have '*technical essentialism*' approaches in common.

Arthur Frank (2004) writes about the gap between qualitative research that is technically correct, and what makes it an engaging, compelling account. The technical approach can lead to work that fails to appear to be worthy of attention, and fails to tell the story of what is important from research, in a way that engages the audience with the stories and accounts being considered (Frank, 2004), highlighting a further consequence in using heavily technical approaches.

For a story to become social science, it needs theory, which involves a tradition of research in which stories hang together in patterns that make sense as a whole, shifting, as the composition of that whole may be. (Frank, 2004, page 435)

There is a need to examine the relationship between research, theory and philosophy of knowledge in qualitative research (Seale, 1999). Qualitative research could be seen as a craft or skill and as such as something that exists by drawing on, but having some independence from social theory (Seale, 1999). For the past 10 years I have been a user and trainer in software to help facilitate the process of qualitative data analysis. My experience in doing this supports Seale's point about research as a craft. I have seen vast numbers of researchers, some new to qualitative research, some experienced, refer to methodological approaches in a way that appears quite unrelated to how they interact with and make sense of data. It is my view that methods and theories need to be separated in order to explicitly make the link between the process of undertaking analysis, and the theoretical influences contributing to the analysis. By this, I mean to describe the various systematic strategies used to engage with data,

but not solely strategies that are prescribed by various methods. I have, for example, commonly seen people drawing on grounded theory and IPA, use very similar strategies to work with data, but it is the theoretical positions that influence the different interpretations of that data, rather than the process of working with the data itself.

Seale (1999) argues that research practice should be seen as independent from issues of philosophical, political or theory position. His point is that the craft of research practice is independent and issues relevant to research, for examples debates on aspects of research such as validity and reliability, could be usefully held across positions, rather than reflecting positions. Here I diverge from Seale's position. I argue that research is not autonomous from theory or philosophical position, but can become so deeply embedded in such things that theory should be separated from craft, so we can be more explicit about how data is interpreted. I argue that when theory is not explicated from craft, the underlying philosophical positions are obscured and become assumptions that may not be articulated in the sense making process. An example of theory and method being used together in ways that confound an analysis is the use of theoretically derived coding structures, which are imposed upon data. In this instance, theory dictates the method of analysis also, leading to an ever decreasing process of consensus. Without space for all strategies and craft required to make sense of data, there is little opportunity for disagreement or divergence from theory, to emerge.

My own experience of realising how easily I had also taken individuals out of their context can be found in the original study from which this thesis has emerged. As I spent time with people with heart failure I came to learn more of their accounts of swollen bodies, breathlessness and brushes with death. In many ways this longitudinal study highlighted that these narratives can become rehearsed and static accounts. What was more difficult to make sense of was the way in which care was organised, regulated, or withheld, and why it was that so many of the people I visited struggled on low incomes, or spoke about their broken hearts in a way that might have contradicted the medical discourses offered to them, and to some extent, by them. By relying on transcript data alone, I struggled to give consideration to the broader context in which people were living and dying with heart failure. It became increasingly important to find ways to include my own experiences and questions about heart failure that could also consider the context in which people were offering their stories.

It also became increasingly clear to me that failing to find ways to contextualise people's experience and the way I engaged with the accounts thereof seemed to steer my analysis towards supporting heavily individual, biomedical accounts of living and dying with heart failure. This is no benign issue, as the use of objectivistic methods and data, and the absence of engaging theory, and led to an analysis that reflected the dominant medical model point of view from which the work originated.

I worked with clinical colleagues who were heavily influenced by medical model world-views, and that impacted how qualitative methods were used in this research. This led to the production of knowledge that was, on some occasions, more consistent with a medical model. An example of this relates to the project design, including conducting interviews with a patient, a carer and a key professional. The way in which the accounts from these three different perspectives were conceptualised illuminates the way in which positivist values can infiltrate qualitative work. Throughout the data there are accounts of patients indicating they have not been told information and this contradicts, at times, the accounts of professionals involved in their care. Whilst the three perspectives could be analysed to offer some insight into how each position conceptualises the sharing of information, positivist notions of objectivity encouraged the privileging of the professionals' account over that of the patient or carer in search of the objective account.

Part way through the research project, an interim report on the findings was prepared. The content of the report was negotiated between me and the research team. One addition by a steering group member to the report of 'preliminary findings' illustrated an assumption that patients may not always be able to understand information, constructing a patient-deficit understanding of when information has not been shared. However such a position assumes that information was shared at all, which it may not have been, or shared in a way that was not accessible. The proposed addition to the report read:

The wish for and ability to assimilate information and the type of information sought by patients and carers is variable.

There was divergence in perspectives about how the collection of three accounts, patient, carer and professional, were understood – that is, three different perspectives in their own right, or the use of professional accounts to get closer to the objective ‘truth’. I found I reverted to notions of how the data ‘speaks’, or in this case does not ‘speak’ to this point. Further I appealed to notions of how ability was not included as criteria for investigation, in a way appealing to positivist notions of how research is formulated and knowledge is substantiated. My case for not including a comment on patient ability was as follows:

We made absolutely no investigation into the different abilities of our participants to understand information – the data does not speak to this and I feel we should avoid making any statement about this.

The final version of the report read that the type of information sought by patients and carers was ‘variable’, which continues to avoid considering how information offered by professionals might vary. However, this debate illustrates how the use of focusing an analysis on what might be considered objective texts, or transcripts, still goes through a highly subjective negotiation of meaning, and one that may be influenced by the unspoken aspects of experience, such as the way in which we may privilege a professional account of sharing information over that of the patient.

If we assume the professional is always more truthful and accurate, then in a situation where the professional claims a diagnosis was shared, and the patient claims it wasn’t, the assumption of patients having limited abilities can become a tempting conclusion. This position supports the dominant biomedical perspective, which makes assumptions about professional practice as competent and patients as inefficient recipients or unwilling participants in those professional practices.

I am arguing that health research that relies on thematic, transcript-based, objectivity orientated methods, runs the risk of the following:

- Analysing the telling of individual subjectivity as a unitary truth.
- Decontextualising people from the knowledge that allow us to consider other perspectives, which have the potential to also explore collective oppressive conditions.
- Privileging dominant discourses that are evident in all accounts, and advancing them as conclusive regardless of the discord with information that is also apparent, but not considered data.
- Replicating, and at times contributing to the creation of, dominant norms.
- Rendering the values, politics, philosophy and theories that influence the researcher, and research, invisible.

Debates over the meaning of so considered 'objective' texts called transcripts has been a persistent influence in the development of the methodology of this thesis. The goal of this thesis was to further analyse a subset of data from this study. The previous study had a strong emphasis on relying on the text of transcripts as the sole source of 'objective' data, and as I have shown, I would also draw on that to defend my analysis to others. However my experiences of being in the field, the informal conversations and interactions, my own observations of the importance of non-textual data, has led me to use a sub-section of the original study data and work with both transcript and non-transcript data to advance my analysis of this material. In doing this, I wish to explore the ways in which we can better understand the impact of the underlying assumptions in qualitative work, and avoid falling into traps of judgement or assumption, that reflect dominant and sometimes oppressive views, about the people we interview.

Many other approaches address the issue of how qualitative research can lead to decontextualizing. Some describe the qualitative researcher as a bricoleur, using a range of tools or strategies to undertake analysis, as influenced by their methodological position (Denzin, 1994; Kincheloe & Berry, 2004; Kincheloe & McLaren, 2002). The concept of bricoleur also considers the centrality of the role of the researcher, and how the researcher also influences the tools used, and the analysis conducted (Denzin, 1994). I was interested in how

to develop qualitative skills that challenge the potential for individualising, and alternatively, grow more comprehensive ground for learning and understanding social processes. In the previous section of this chapter I outlined how the person, or subject of research, can become described as unable to understand information, as opposed to not being told information. Such an account makes certain types of participants, namely patients, vulnerable to being perpetually discredited, and their accounts always contested. How such a process leads to subjugation of participants in research is key to this thesis. By subjection, I mean the way in which dominant perspectives can be expressed through research, and in ways that may control or oppress others, including those we research. The challenge emerges, however, about how to find different ways in which to explore subjectivity, and how qualitative methods can grow our learning about different experiences and contexts.

If we broaden, and deepen the social contexts in which we explore subjectivity, we will discover gaps, slips, and sidelines similar to those Freud found in the psyche, famously calling their emanations “the psychopathology of every day life”. Being able to see such gaps is important because they contain places where subjection fails to hold. (Martin, 2007)

In the following section I will outline the approach I have taken in this analysis. A key influence for me in proposing this approach is the work of Bakhtin (1981). Bakhtin was a Russian literary philosopher, and his ideas contribute much to how I, as a qualitative researcher, obtain, analyse and retell accounts from participants and about myself. I have drawn on Bakhtin as a way to emphasize the importance of context, including non-verbal context, in the process of working with and analysing data.

When working with qualitative data, I argue we are essentially engaging with, or reflecting different perspectives on, how language is understood, or made sense of. Bakhtin describes language as being dialectically constructed through the context in which the word is from, spoken and used. In conversation with a research participant, they speak as they do because of who they are, and who they perceive the audience, or researcher, to also be. As we speak as researchers, we speak in ways that include the context of all we see and know about that person, even if it is never verbalised. In this work, those contexts included people living in areas of visibly high socioeconomic disadvantage, which becomes part of the unspoken context

that influences the words and language that is used in the research interview exchange. In one example I interviewed a participant who told me about the moment he learned he was dying from his heart failure. We spoke whilst his 11 year old grandson was in the room, and this invisible, silent audience had an enormous influence on the exchanges we were able to have, even though the grandson's presence was not apparent from the transcript.

Dorothy Smith (1999; 2005) draws on Bakhtin in her account of institutional ethnography, additionally she focuses on the influence of dialogism on the activation of text and the relationship between text and the reader. When I interviewed one participant, I was fairly sure he did not know his diagnosis of heart failure. Later, when I learned that he had always known it, it reframed my reading of our interactions and led me to activate his text in different ways.

Here I am arguing that there needs to be a role for different types of knowledge in relation to qualitative data analysis that allow us to consider the research participant, but also makes a place to consider the researcher (as addressee), and the role of broader social context and theory (as the superaddressee). By doing this perhaps there is a potential to move towards integrating the dialectical nature of language and knowledge into our analysis and reduce the risk of monologism, which tends to render invisible the influence of these invisible audiences.

Smith makes the case that texts are activated to serve the institutional order (Campbell & Gregor, 2002; Smith, 1999, 2005) as seen in the way a referral form for palliative care might be designed – which is often with pain as a factor for eligibility, which may not always apply to people with heart failure. The forms then raise, or activate, an idea that specialist palliative care may be needed primarily when there are issues of pain control. This could be criteria which might be less relevant to people with heart failure, but provides a rationale for inclusion or exclusion from the hospice service. I think in research the focus on developing procedure-based methods in which to activate texts in ways that favour the idea of achieving objectivity, along with the privileging of what texts to activate, serves to in fact deactivate the text in order to serve the research or institutional agenda. Mostly this is achieved through deactivating the reader or researcher, due to ways in which the role of the researcher, or reader, is underemphasised. Next I go on to describe the three strategies I have used in conducting my data analysis, and how I have attempted to integrate a dialogical approach into the process of conducting my analysis.

2.5 Dialogical Integrative Analysis Method

In this section I will outline the methods I have drawn on to further extend my definition and analysis of data. I am proposing a method in this work, called the dialogical integrative analysis method, or DIA Method, that aims to look for those '*gaps, slips and sidelines*' that Emily Martin describes (Martin, 2007) as offering insight into the places that '*subjection fails to hold*'. I will outline the three-part strategy of analysis that I used for my thesis, which included defining data, activating the self/analyst and placing the analysis in conversation with theory and social context. These three parts are the central elements of the dialogical integrative analysis strategy. This strategy is not meant to be definitive, but rather to outline the various processes of ways to engage with the data analysis. Frank (2005) suggests that there is no way to offer procedures to achieve dialogical research, as that in itself would only lead to a monologism. Whilst that perspective does have many merits, I suggest in a world of '*technical essentialism*', as described by Barbour (2003), we can use the ideas of such technical or procedural suggestions to promote dialogical perspectives in research. However, my aim is to propose processes that can help researchers retain ways to keeping dialogism open, or as Frank (2005) describes, to keep the character alive. The processes I have suggested, could contribute to describing the character dialogically, and in that social and historical context.

2.5.1 Defining Data

The first aspect of my approach to data analysis was to revisit and define what I regarded as data. In the original study, data was largely defined as interview transcripts, which were systematically analysed for themes occurring in the data. For this study I focused on data from interviews, my observations, textual data such as newspaper articles and patient information (textual and DVD). The strategies I engaged to work with the data included systematically reviewing the data and considering:

- Identification of themes and subthemes.
- Foucauldian discourse analysis, to analyse discourse, or the ways in which language is constructed, often reflecting a production of broader social meanings or norms.

- Utterances, or the way in which language may be used in specific ways, particularly in relation to performance.
- Relationships between individuals, and how those relationships mediate the flow of discourses, utterances and performance.

Here I have taken the approach of defining the unit of analysis at an ‘utterance’. Bakhtin refers to the idea of the utterance as an interchange where meaning is made, and exchanged, embedded in a historical context (Bakhtin, 1981; Holquist, 1990). In this context utterances should not be understood as transcripts alone, as these are static and exclude non verbal narratives, exclude social cues, wider ethnographic observations and meta-reflections. In this sense I am arguing that data should have a dialogical potential, in that transcripts should be located in a broader context when possible, and the researcher should identify and define that context.

Using the strategies above I worked with the dataset of 122 interview transcripts and additional data sources as outlined. QSR NVivo software was used to facilitate this analysis (version NVivo7 and 8). Through several iterations of analysis, 330 nodes were developed during the process of systematically working with the data. The data for each participant (patient, carer and professional interviews), was organised into data sets or cases. The level of coding for each set varied greatly, and this variation was influenced by the amount of data collected. This ranged, for example, from one participant set including two interviews and being coded by 12 nodes, or themes, on 19 instances, through to nine transcripts being coded by 33 nodes, at up to 288 instances. Analysed data included field notes that were made for each interview. Multimedia data was not analysed using NVivo, as at that time it was not able to work with those data. Relationships and patterns were explored through the data set through using search functions and modelling tool, allowing for relationships between themes, or between types of participants, to be identified.

2.5.2 Activating the Self/Analyst

The second aspect of analysis is based on Dorothy E Smith’s (2005) work on the activation of texts, which suggests that the role of texts as data can only be understood by considering non-textual information as well (Campbell & Gregor, 2002; Diamond, 1995). The activation of texts

is contextual, and temporal, in that texts can be reactivated depending on when and how they are activated in the first instance. An example of how the notion of activating texts can inform analysis could be as follows. Allan and I had a great deal of discussion about the state of his heart and his heart problems. Due to the ethical commitment not to mention heart failure, unless the participant did so first, I questioned him broadly and he never used the words heart failure. I was fairly sure he did not know he had heart failure, as was very common to many of the people who participated in this research. The content of the interview transcripts would support that view. In one of our interviews he described his approach to living and dying, in that you cannot just 'face the wall', but you have to continue to get on with things if you want to live.

Allan: And her friend ... she died just lately, but I don't know if you've heard the old expression she turned to the wall, in other words she wasn't fussy.

RP: Right she kind of gave up a bit....and it sounds like you're someone who doesn't want to put your face to the wall either?

Allan: Oh no.

RP: You're about the opposite of that?

Allan: Aye I like to get on with things you know.

One day I spoke to Allan to arrange a follow up interview, he asked me if I had called to see if he had died from his heart failure yet, and so had indeed known that he had heart failure and that I was interested in talking to people with end stage heart failure. This offered a new context that activated the text for me, differently. I think turning to face the wall means something different when you are talking about a general attitude to living and dying, but to express it in relation to living with a terminal diagnosis of heart failure, may speak more to having a fighting attitude. You are not just turning to the wall away from life in general, but you could turn to face the wall in relation to bad news, which Allan said he was determined not to do.

Part of my approach to understanding how I have activated the text, or data I collected, is to identify the self also as a subject in this research. Haraway states that '*only partial perspective promises objectivity*' (1988, page 583) and in qualitative methods, I suggest that including the self as a subject also is essential to situate an analysis in the context of how that knowledge is generated.

Situated knowledges require that the object of knowledge be pictured as an actor and agent, not as a screen or a ground or resource, never finally as slave to the master that closes off the dialectic in his unique agency and his authorship of 'objective' knowledge. (Haraway, 1988, page 592).

Engaging with the role of the self has been widely acknowledged as important in qualitative work and mainly described as reflexivity, and is often considered a defining feature of what makes quality qualitative research (Henwood & Pidgeon, 1992). Reflexivity can be described in many different ways, Willig (2001) describes it two ways, being, personal reflexivity and epistemological reflexivity (Willig, 2001), both of which is undertaken to encourage researchers to consider the ways in which their research is influenced by who they are personally, and by the approaches they use (Willig, 2001). There is much variation as to the level of importance placed on reflexivity (Willig, 2001), and the approach a researcher takes to reflexivity is influenced by the theoretical stance taken in the research (Finlay, 2002). There are differences, for example, between the role of subjectivity in social constructionist, psychodynamic and participative approaches (Finlay, 2002). Some approaches, such as psychodynamic, may focus more on personal experience and encourage inward looking processes of reflexivity (Finlay, 2002). In contrast some social constructionist approaches (of which there are a variety of versions) consider the role of structural influences on the researcher, and participatory approaches encourage reflexivity to consider research as a co-construction of knowledge between researcher and research participants (Finlay, 2002). Others describe the main differences in the approach to reflexivity as varying between relativist and realist approaches, with relativist being located in postmodern perspectives on narrative, and realist relying on a sense of researcher confession (Gough, 2003).

In this thesis I refer to reflexivity as it is used to describe the historic and institutional conditions in which the research is conducted (Parker, 2005). Reflexivity in this sense differs from the integration of researcher subjectivity alone, which can be criticised for being problematic in the development of individualising accounts in relation to research (Parker, 2005). Critical reflexivity also requires the consideration of the relations of power between participants, researcher and the institutions in which the research is situated (Parker, 2005).

For this study I have attempted to integrate my experiences, my relationship with participants, the data and the analysis throughout. The process for doing this involved including my observations as data in their own right, and attempting to reflect critically on the historical and institutional conditions in which I have engaged with the analysis.

2.5.3 Being in Conversation with Theory and Context

The third key aspect for this proposed Dialogical Integrative Analysis Method is to consider the analysis in relation to theory and broader context. This means to identify the key theoretical influences that I have drawn on in undertaking my analysis, but as distinct from the process of working with data. In other words I am arguing that the process of analysing data should be distinct from, but in a dialectical relationship with both theory and a broader context, such as epidemiological data. I also suggest that considering more than just one theoretical perspective is useful for offering more opportunities to explore how our analyses develop in a dialectical process.

I have tried to achieve this throughout this thesis by integrating and exploring different theoretical perspectives, essentially placing my data, and myself in conversation with more than one theoretical perspective. By doing this I'm trying to open my analysis to Bakhtin's idea of the superaddressee (Bakhtin, 1981; Holquist, 1990), by explicitly identifying that overarching set of values or ideas which my analysis may be in conversation with. Likewise, the inclusion of social epidemiological data as to the societal context of the focus of research is equally important. Doing so may help identify exactly who we are generalising about, particularly when we default to generalising in qualitative research (an issue further emphasised when conducting such work as meta reviews). In the case of heart failure, those generalisations can fail to address dynamics of class, ethnicity and gender.

The theorist whose ideas I have drawn on most in this thesis is Foucault, and I have found his approach useful for informing a conversation about the role of discourses (Armstrong, 1997; Foucault, 1976, 1977; Hook, 2004), particularly drawing on these ideas in relation to the creation of the 'subject', which can in turn lead to the subjugation of the people we research, or a process of holding people against broader social norms, that usually serve dominant group

interests. Thus Foucauldian discourse analysis has been engaged to explore discourses in relation to heart failure. I have also placed this analysis in conversation with the work of Butler (1999, 2000, 2005), in particular in relation to the way in which performativity informs our learning about being a patient living and dying with heart failure. I have also drawn on Farmer (1999, 2004) and his theories of structural violence, Smith's (1999, 2005) work on institutional ethnography and Bakhtin's dialogical approach (Bakhtin, 1981; Holquist, 1990).

2.6 Summary of the Dialogical Integrative Analysis Method

In summary I am conceptualising a three part process of analysis, and describing it as Dialogical Integrative Analysis Method.

- This approach argues it is essential to explicitly define data, and to consider data as much more than just interview transcripts, but as dialogical units of meaning, which may require more than interview data alone in order to offer useful contexts with which to base analyses on.
- I then argue that identifying the activation of the role undertaken by the self or analyst is essential, and the inclusion of the self as also a subject of the research may be useful. Such an approach should encourage the integration of the self into analysis, which can contribute towards exploring a situated knowledge, which would be able to integrate the dialogical processes of both producing data, and reflecting on theory.
- Finally I argue that analysis must be placed in a broader context of being in conversation with theory and social context such as (but not limited to) social epidemiological information. These sources of information illustrate the superaddressees that are present in the analysis, for the self and for the research participants.

I see the relationship between these three aspects as being intertwined and overlapping, although no aspect alone allows for anything other than a partial perspective.

2.7 Ethics

Ethical approval was sought and granted for this research by an NHS Lothian ethics committee. A number of safeguards were put in place to ensure the research would be conducted in a way that was considered ethically appropriate. This included providing assurances that participants would not be informed that it was a project focused on either palliative care or heart failure directly. This is a common assurance and aims to safeguard against the accidental disclosure of information that a participant may not know in relation to their diagnosis or prognosis.

2.7.1 Informed Consent

The study team and I were aware that there was a great deal of variability in the disclosure of the diagnosis of heart failure to patients. We committed to ensuring that we would not at any stage risk disclosing the diagnosis to a participant or carer just in case they did not know it. On written information, such as the patient information sheet, this meant the study was described as considering 'heart problems'. The written study information sheet described the research as follows:

'More and more people are experiencing heart problems and we need to find out how best to help people with this condition. We want to learn about what it is like to have heart problems or to be close to someone with heart problems'

When interviewing people I never mentioned the term heart failure unless they did so first, instead I talked about heart problems or serious heart problems. If the participant mentioned heart failure, I would then use the term in the interview and asked what people understood by and felt about this condition. Equally, I never mentioned palliative care or end of life issues, unless the participant broached this, although I would ask people about their thoughts or concerns about their future.

Not fully disclosing the purpose of the research did seem appropriate, particularly given the extent of non disclosure of the diagnosis or prognosis of heart failure. However it did feel

challenging to be talking with people whilst presenting a degree of misinformation about why I was there. In some ways it felt like such an approach did not achieve fully informed consent, however without taking that approach the research would have excluded the many people who are not informed of their diagnosis. Additionally, this negotiated process of mentioning topics that might lead us to talk about heart failure and end of life issues, sometimes led to some confusion. Some participants appeared not to know that they had heart failure, or that it was so serious – and yet subsequent exchanges would reveal they had known both things, but since I couldn't ask explicitly about it, may not have emerged during an interview.

In one interview I had gently broached the topics of 'thoughts or concerns about the future', and the participant, Peter, avoided answering. Our interviews were quite dynamic and almost playful, and it was unlikely he would answer such a question unless asked directly. Eventually he showed he knew what I wanted us to talk about, but also illustrated how you can ask directly about approaching the end of life by recounting to me an exchange he had with his doctor.

Peter: My doctor once asked me that, he says 'do you worry about dying?'

RP: Right...

Peter: 'Are you afraid you're going to die?' And I said, 'no. I'm not afraid I'm going to die', I said, 'I'll be quite honest with you. I don't want to die but if I'm going to die I've no worries'. I said, 'I'm not frightened to die, but I want to live.'

Whilst overall, I have to agree that it was right to not ask people directly about heart failure and dying, given how many people did not know this information it did introduce an uncomfortable dynamic into conducting the work. Part of that discomfort for me, was how I replicated in my research interview certain practices I have argued are paternalistic, i.e., withholding information from people about their diagnosis and prognosis, particularly in relation to previous work I had conducted in the field of dementia (Pratt & Wilkinson, 2001, 2003).

2.7.2 Ethical Challenges

Throughout this project there were times that dilemmas arose about when to act outside of my role as a researcher. An example of this includes when I went to visit May one day at her home, and she was very poorly. She felt too unwell for us to have an interview as such, but I stayed with her a little while and got her a drink and made sure she was comfortable. Feeling concerned about how she was, I asked her permission for me to phone her heart failure nurse specialist, and she agreed to let me contact her nurse.

In many ways the example with May is straightforward, she knew she had heart failure, and had a named nurse I knew, and could contact. However more complicated issues arose also. I met with Brian three times, and despite having heart failure (which he knew), he was described by his heart failure nurse specialist as really quite stable and well. I also met with and interviewed Brian's son three times. Brian's son was not well informed about his father's health, although the relationship between them was excellent. The son felt that Brian was actually facing imminent death, and felt quite anxious and depressed about this possibility. He felt each time the phone rang, it would be about his father, or worried that if he went to visit he would find his father dead in his home. It was quite clear that a misunderstanding had come about through a lack of communication as Brian had no reservations about sharing information with his son. In this case I talked with his son about his involvement in medical appointments, such as heart failure nurse visits, and explored with him the possibility of talking with his father about sitting in on such appointments, if that arrangement was suitable to both. However no information from Brian, or his nurse, was disclosed at any point and the discussion originated from an ethical obligation to talk with the carer given his clear but unnecessary distress. This also highlights the potential gaining of support through the interview process itself, both by using talking about experience as a form of coping, and helping with thinking through various issues relating to care.

The most challenging ethical dilemma though, was being confronted by the practices leading up to Linda's death, as described in section 1.1 in the introduction. I felt most unprepared for what to do in the face of an alleged malpractice. What I did do, as discussed earlier in this thesis was to bring the concerns to the research project steering committee to explore our

obligations and potential actions. However, when researching health care, it may be that ethical guidance should be given in relation to addressing such issues, for researchers and grant holders. The way in which Linda's carer's concerns of poor practice were dealt with, did serve to illustrate both how vulnerable Linda was, and how institutionalised responses (via myself as the researcher), run a risk of deferring to the interests of those institutions.

I will now move on to present the findings from this thesis across the next five chapters. The first is an exploration of daily life with heart failure, and how we begin to construct the subject. This exploration will move between descriptive accounts and more theoretically based reflections.

3 Daily Life with Heart Failure: Constructing the Subject

Another one again!

(Carol) - coming from the (local general hospital) to ward X today. Young woman, in her 60s with v. bad heart failure, a previous leg amputation and a recurrent pleural effusion (where fluid builds up inside the chest, but outside the lung). She's very miserable and lots of end of life issues.

Husband cares for her at home. Not yet asked her - but she would certainly be able to paint a gruesome picture of how rotten life is at present. (Email from Carol's geriatrician referring her into the study)

I knew very little about heart failure before undertaking this research, despite having my own strong family history of heart problems. I had been drawn to undertaking this research through a combination of interest and circumstance, and quickly learnt that heart failure was far more common and serious than I knew. This chapter aims to lay a foundation of what daily life with heart failure is like, providing a context from which further analysis will develop. It also reflects my own learning in relation to the uneven paces of daily living with heart failure, and how the way we approach trying to understand experience, influences the type of knowledge we do, and do not, privilege.

Throughout this chapter I will draw on ideas about how people might be individualized through research, and what consequences might arise in doing that. Qualitative research draws on different understandings of the epistemological and ontological basis through which we construct various explanations of subjectivity and experience in different ways (Willig, 2001). Those understandings might be used to influence people's lives, and in some cases be used to justify the way services are shaped, or how care is given. I have only begun to touch on some of those issues in this thesis, and the structure of this thesis shows my own process of learning about the experience of living with and dying from heart failure. In this chapter I show how that learning would start with meeting heart failure patients, like Carol, on wards in local

hospitals. The first part of this chapter offers a descriptive account of living with heart failure that is typical of much qualitative research, and then goes on to argue whilst such context is helpful, it is necessary to further that analysis by considering a range of different perspectives that can broaden our thinking about living with and dying from heart failure.

3.1 Describing Daily Life

The first patient I met on an inpatient admission was Carol. Carol seemed different from other patients in this geriatric hospital as being in her early 60's, she was by far the youngest person on the ward. Carol's heart problems had developed over the past eight years, with difficulties including an irregular heart beat and angina. Carol stood out in the context of a geriatric ward, where she was clearly relatively young. Her account of a long gradual process of heart problems leading up to the point at which heart failure was diagnosed is typical in this research and in the literature (Rodriguez et al, 2008; Thornhill, Lyons, Nouwen, & Lip, 2008). Carol was unhappy to be on the ward and didn't want to be there, stating she was only taken to hospital as she was unconscious, and therefore unable to object.

Whilst Carol's heart failure had developed over 8 years, for others it developed over a much longer period of time. When Helen described to me her experiences of living with heart problems it was a story with a 20 year history. Her story was clear and somewhat static; as if it had been told and retold a number of times over the years, to a range of audiences. For Helen, now in her 70's, the first signs of difficulties with her heart came when she was visiting her mother in hospital, and as Helen described it, '*took terrible chest pains*'. This marked the start of a 20 year period of managing painful angina attacks, through which periods of stability were punctuated by times of medical intervention, such as restarting the heart to regulate the heartbeat in hospital.

They put it down to angina at the beginning, right, and I was put onto drugs and what not, but I would have so long good and then I would really have maybe a bad spell, and nine out of ten times I would be carted back into the (hospital). I had a few cardiac intermissions because I wasn't right and they just couldn't understand it. At first they thought I had a lazy muscle at the heart that was causing all this, but as time progressed it wasn't so much lazy muscle, I mean I had a very good Consultant and he

was really very good, and I never felt you know, sometimes you can feel quite frightened when all this starts, and he put me at ease right away... Uh, it was like as if I had a car engine running in here, and it wouldn't stop. It was a horrible feeling and again, they would always get me sorted out again and that's how it went on for years. (Helen).

Helen's daily life now consisted of sitting in her first floor council flat, she rarely left her house; and felt stranded by poor mobility, particularly as she lived at the top of a flight of stairs she could not easily navigate. Her heart failure was described as stable by the medical professionals who referred her into the study, but she felt isolated, unable to leave her home without help due to breathlessness, was in pain and had a fear of 'taking a turn'. The long accounts of repeated 'turns' or acute episodes led to feelings of low confidence, and worry about the impact of physical exertion. The increasing limitations and restrictions led to feelings of frustration, loss, anger and isolation, which is also commonly reported in the literature (Murray et al., 2002; Thornhill, et al., 2008).

Less usual, was the experience of developing heart failure in a way that was sudden and unexpected. For Louise, the first time she had noticed any difficulties with her heart resulted in an emergency admission for chest pain and breathlessness, and at this point she was diagnosed with heart failure. Louise came to learn she had heart failure after being assigned a heart failure nurse specialist. People who had long accounts of living with heart failure over lengthy periods of time, also spoke of the experience of acute events that characterized an unstable state of health that accompanies living with heart failure.

A range of cardiac issues were a common precursor to developing heart failure. May described how she had experienced only four days without the pain of severe angina attacks over the last 14 years of her life. During this time she had experienced many admissions to hospital, a range of surgical procedures (both for her heart and for the management of pain). Living with persistent pain led her to feel that life had become no longer worth living. May and others, spoke of undergoing many surgeries to help manage their long standing coronary challenges. Daily life with heart failure was characterised by a range of challenging physical symptoms, including difficulties breathing, fluid retention, fatigue, pain, dizziness and irregular heartbeat, for many of the participants.

Carol described herself as restricted in her movement and activities. She talked about how she didn't like having to rely on others to care for her, and wished she could be at her own home, where she felt she would get better much faster. She was agitated at being in the ward, and as we spoke she would move between being angry, to crying. Carol had, like many people with heart failure, experienced periods of poor health mixed with times of better health. Often a hospital admission, like the one she was on when we met, would be involved in the times of poor health. Despite Carol standing out for her relative youth, this vacillating state of health also marked an overall slow deterioration in her health. After meeting her partner Ray, I invited him to get in touch, even by email if he had any other thoughts he wished to contribute to the research. He, wrote to me after I interviewed him and Carol together, and outlined his experience of the gradual decline in Carol's health, particularly over the last 18 months. His account of Carol's decline shows how profound the impact of heart failure can be for the person with heart failure, but also for those who are carers. It also highlights the frustrating and complex transition in the relationships as increasing levels of dependence and care unfold with the progression of heart failure, which is again reflected in the literature (Thornhill, et al., 2008).

Daily routine (then and now)

THEN

08.00hrs. Get up and get the wife up and to the toilet where she does the necessary for herself while I get breakfast. During this time she sorts her medication takes her blood/sugar and insulin.

09.00hrs. Clear the table put the dishes in the sink and hope they wash themselves. Ensure the wife is settled where she wants to be and position the commode as she does her own transfers and go to the shops.

10.00-12.00hrs. Generally potter around doing the bits and pieces here and there. Go to the bakers and pick up pies or rolls to have with a cuppa. Give the wife her medicine bag to get her midday pills etc.

13.00-18.00hrs. During this period you do all the things you have missed as well as prepare the evening meal.

19.00-22.00hrs. After eating clear the kitchen etc.

Ensure she has her medicine bag to hand, and go to play the computer and relax. Keep a check on her once in a while but not when the soaps are on.

22.00-08.00hrs. Fix some supper, make sure she is settled and go to bed.

NOW

08.00-10.00hrs. Normally wake in a bad mood as it is normal to have been up several times during the night.

Empty the urine bag clean the commode. There is no need to dress as I sleep fully clothed on the sofa. Wash and make a cupper. Sort out mine and wife's tablets plus set and administer her insulin. Help with her washing and changing herself. Make breakfast and wash up. Tidy up for the nurse coming in. Transfer to and from the commode clean as necessary as and when required.

10.00-13.00hrs. More transferring as required plus making tea and snacks. Make sure the nurse has got her seat and table for her bits to hand, potter around tidying up before the home help comes, why I don't know as this is their job, when the home help comes in I can get out for about an hour to do the shopping. Each one is part of a care team and are capable of dealing with personal needs. I have given them free run of the house on an if you think it needs done do it basis and it works well. By using this method it shows that you are relying on their know how and that you trust them by giving them free scope to do the job. I'm normally back in the house by 12.20hrs and prepare the midday snack.

13.00-18.00hrs. During this period I am doing transfers, seeing to her needs and preparing the evening meal, getting her medication and mine ready and ensuring that it is taken.

18.00-22.00hrs. This is when I am supposed to take a bit of time for myself but never seems to happen. At 18.00hrs I log on the computer check the mail etc. play cards and try to relax for a while. During this period I can be up and down the stairs every 20 minutes for things like the toilet, tea or lost glasses etc. Instead of relaxing I get wound up because I think I am being played for a fool. Tempers get frayed and things get said that should not be said. Around 22.00hrs I get the final medication ready, fix a supper and change the leg dressing, empty the urine bag and settle her down for the night.

22.00-08.00hrs. The above can take up to and over an hour to complete depending on what's to be done. As stated I sleep fully clothed on the sofa just in case I have to get the emergency services out and see to the wife until they arrive which I have had to do several times in the past. When I settle for the night it is usually around 00.30hrs in the morning knowing that I will be wakened at least 2-3 times during the night every night.

Then and Now covers a period of approx 12-18 months the last 7 of which has shown the most signs of her condition deteriorating to today's level. She has moved from a person with a high degree of mobility and independence to a person who has become totally dependent on other people for everything.

(Email from Ray)

I had not fully appreciated the way in which heart failure could lead to a slow and unsteady decline, which would have such a significant impact on daily life. In times of poor health, people lived with uncomfortable symptoms and hospital admissions. In times of good health, people were less restricted, but lived with a constant threat of imminent decline. The journey and difficulties that Carol lived with were typical of many people in this research and in the literature (Thornhill, et al., 2008).

Heart failure is rarely the only physical condition or illness that a people will be living with. I came to gain a new understanding of the complex and interrelated nature of the body, the wear and strain that is both caused by and contributes to cardiac difficulties. Difficulties with the heart could lead to other common health conditions, such as diabetes or renal failure. For Carol, her physical health was deteriorating and she was suffering from diabetes, leg pain, mini-strokes and serious nose bleeds, alongside her heart failure. Other conditions described by participants included dementia, hearing loss, mobility problems, cancer, pain, Parkinson's disease and chronic obstructive pulmonary disease (COPD).

As the body fluctuated in times of good and poor health, so did people's more general emotional sense of wellbeing. Constant adaptation and challenge was reflected in contrasting narratives of hope and despair. In this study and in the wider literature people described living with a constant fear of deterioration, including fears of becoming too breathless, leading to descriptions of fear of drowning in the fluid of their own lungs. Participants reported a wide variety of emotional responses to living with heart failure, including anger, frustration, anxiety, loss of confidence, low mood, social isolation, thoughts of dying, panic, worry about the future and frustration from looking well to others whilst actually feeling very restricted. These challenges to emotional wellbeing were all also reflected in the broader literature (Ryan & Farrelly, 2009; Selman, et al., 2007; Thornhill, et al., 2008).

Financial consequences of living with heart failure, including increased costs, and forced early retirement have been reported (Horowitz et al, 2004; Rodriguez et al., 2008; Thornhill, et al., 2008). Participants in this research echoed these concerns, along with emphasising the potential of forced retirement, where people had to stop work against their wishes. Participants described difficulties in obtaining disability allowance benefits or assistance for issues, such as the installation of a stair lift, as the days in which you might be assessed, could be among one of the good days. Some described how even on a bad day they might still look fine and able, and feel scrutinized for taking a designated disabled persons seat, or would feel their slowness was seen as obstructive. Heart failure led to variations in health and serious restrictions that might not always be visible to others, leading to a feeling of hidden disability.

One particular aspect of the financial impact, was the resources required to make adaptations to overcome challenges in daily life, including adaptations to buildings, bathrooms, staircases

and entryways. Some people were very aware that they might die before they were likely to receive life enhancing adaptations to their accommodation, particularly if relying on local authority assistance for paying for changes. As May lived in rented sheltered housing, she felt it was not her responsibility to pay for the essential adaptation of a walk in shower herself. She felt she might die before she would get this important adaptation, and she did indeed die before the shower was installed. Allan died whilst waiting for a stair lift to be installed. The stair lift would have made it easier for him to reach his bedroom and bathroom from the main floor of his home. The length of time taken to modify homes could have a serious negative impact on the potential quality of daily life of participants.

The lack of ability to obtain and cook your own food, was also a challenge to the identity of some participants, particularly women, where there had been a sense of self attached to the preparation of meals for themselves and their families. This made it a particularly difficult transition to be relying on food prepared by someone else. For participants that lived alone, there might be a reliance on services such as meals on wheels, which were often described as unappealing, or not consistent with the dietary needs for those with heart failure or for those who also had diabetes. On visits with different people I saw non-identifiable food, which had been delivered by meals on wheels, being fed to the family pet, which was one way of making use of the food provided, and no doubt acted as a comment on the quality of the food. Even if people were able to cook for themselves, finding a way to get to a supermarket to purchase food was often difficult due to problems some participants experienced with mobility.

The data I collected equally reflected that people lived with fragility and had to cope with the idea that their heart might become seriously unreliable at any time, causing deterioration or death. These feelings were described both by those that knew their diagnosis of heart failure, as well as those who did not. People talked about feeling down, getting fed up and being depressed and upset, as they experienced becoming stuck in their home or facing stays in hospital. The fluctuating levels of independence or dependence were often difficult to deal with. Frank described his struggle to manage the physical consequences of heart failure, as: *'it doesn't do my morale any good.'* Or as Ian reflected, the loss of being able to do what you used to be able to do, could get you down.

Well I've been feeling a bit low, yes a bit down, but that's only because I just can't do anything, you know? That is a bit frustrating to, you know and it does get you down, because you can't do a thing, you know? (Ian)

I had the sense that the way Carol coped with the variable nature of her health was to rage. She seemed angry at her situation, at her husband and at those providing medical care to her. During an interview with Carol and her husband Ray, the tension was so noticeable I was concerned they were about to escalate into a serious argument. Carol would move quickly between depression and anger, at times raging, or at other times weeping. She also felt she might just depress others if she talked openly about her feelings.

I'm sitting here and I'm just depressing you. (Carol)

People described many ways of coping with this turmoil. Allan felt that you could either choose to just “get on with things’ and as mentioned in Chapter 2 (2.4.2), fight your prognosis, or you could ‘turn to the wall’, which would be the same as conceding defeat to the illness, and would in his view, contribute to a hastened death. There were other ways that people found a reprieve from the sometimes painful experience of the heart difficulties. May, when the pain of her angina became unbearable, would arrange to be alone and drink oral morphine, which was prescribed both for pain and breathing difficulties. She would prepare for this time by making a coffee and going to bed, and let the medication ‘unwind’ the pain she was experiencing.

When I'm in pain I don't like anybody in the house ... I just like to make myself a cup of coffee, and take my morphine and just hold on to unwind. Because it's quite a whirlwind, and it gets really bad and then the morphine, slow, slow, slow, and then it eases up. Without it there's nothing that puts it away but the morphine. (May)

Some participants talked openly with me about how they felt about living with heart problems, whilst others didn't. Ian described how talking about emotions could make it hard for his family, and harder for him to cope with his frustrations. Some people, such as Frank, felt the opportunity of participating in an interview offered a chance to talk about his feelings, to get it all off his chest, and this highlighted the sometimes limited opportunities to talk about feelings.

In that sense, participating in an interview may have also been one way of helping to cope with, or reflect on feelings.

Another way of confronting the difficulties of life with heart failure was to count your assets rather than your deficits, to focus on what you still could do, and not what you couldn't. For some Helen this included appreciating what you do have, as there is always someone in a situation that is worse than your own.

Having seen others suffer so much, you know, it makes you feel very grateful for what you have. (Helen)

This picture of daily life with heart failure offers some insights into the daily challenges that face people living with heart failure. The findings have emerged from describing the broad thematic analysis of the data, and aspects of those findings have been described in a publication elsewhere (Boyd, et al., 2009). However, for me, there was still much that was not explored or developed through trying to understand heart failure this way, although this descriptive context is very useful to acknowledge and offers a base for further analysis. Next, I go on to reflect how work such as this, and other research studies, offer what can be seen as a growing consensus about the experience of living with heart failure, and explore some of the problems we may encounter by taking this view.

3.2 From Findings to Theories

I felt I learnt a great deal about what it could be like to live with heart failure as an individual. My findings were focused on understanding subjective experience, based wholly on the analysis of transcript texts generated from conversations with patients, carers and professionals about heart failure. They resonated well with the growing literature and reviews (Welstand, et al., 2009; Yu, et al., 2008) and the temptation arises from such a growing consensus in the literature to draw conclusions about what we 'know' about heart failure. Alternatively this body of knowledge could be described as a growing collection of studies that

approach the same topic of enquiry, with the same method of enquiry. By illuminating the experience of heart failure through these similar methods, and methods which I have drawn on myself in this chapter, there becomes an emerging sense that the subjective experience of people living with heart failure is becoming well understood. This growing consistency around the subjective experience begins to lay the foundation for establishing the norms of what it means to live with heart failure.

Norms could be described as the information around us, that comes from the broader social and cultural context, and define who we are subjectively, or as subjects. Norms guide our sense of what might define a person, offering the contrast between what is expected (norms) and what is outside of that. Comprehensive examples of how norms may define both who we are, and how we are expected to behave, can be found embedded in discourses on sexuality (Foucault, 1976), gender (Butler, 2005) and mental illness (Martin, 2007). Martin's discussion of the development of the norms for people with bipolar disorder illustrates how powerful establishing such norms can be. For example, one of the norms that defines bipolar disorder is that of being irrational, with discourses reinforcing the idea of mood variations leading to contradictory and irrational behaviour (Martin, 2007). Should we accept this norm, and it is widely accepted, then the experience of being a person labelled as having bipolar disorder, is by definition that of being understood as irrational. This example serves to illustrate how norms can be powerful, as in the case of bipolar disorder, the person who is labelled as having bipolar disorder cannot disagree with any norms established about them without also being seen as reinforcing the idea that they are irrational, and therefore a non credible subject (Martin, 2007).

Norms feature in our social context, are frequently unspoken. They are the taken for granted expectations and understandings about how people act, behave and think. When I would interview a person for this research they were often older and from areas of higher deprivation than me. I would arrive and be different in some obvious ways, I was younger than them and was a foreigner, being from New Zealand. Because I had a New Zealand accent, participants found it hard to ascertain my class identity from the way I spoke. Many participants took me, this displaced young lassie, into their homes, making me sandwiches, offering me home baked cakes, cups of tea, tours around the garden and showing me their family photo albums. For some of these interviews it came up that I had a new baby, and often I would be asked if I had

met a nice Scottish boy, is this your first baby, and have you decided to settle down? Indeed this was not the case. I had met a nice woman, this was our first child together, and my partner's first pregnancy, but, yes we were settled. The reasons I did not clarify this to my participants brings the idea of norms into the exchange. I did not want to disrupt the research interview exchange by raising the topic of my difference against the norm. This does not necessarily reflect the actual views of any of the people I interviewed, the point is that the reasons why it would be potentially disruptive to an interview do not even need to be stated. Norms are collectively held and known, formed in many ways and reflective of majority experiences, views and beliefs. The ways we express, reject, perform and resist such norms, is a central to the way we understand identity.

In many ways, my own attempt to describe life with heart failure has contributed to developing a description of the norm of living with heart failure (Boyd, et al., 2009). My own work has reported findings which help explore the experience of the person living with heart failure, and contribute to how we understand the experience of people with heart failure, much in the same way as other similar efforts in the literature do (Welstand, et al., 2009). Here, in this chapter, Carol provided a central example of the '*gruesome picture of how rotten life is*' with heart failure and I have used examples from other participants in the study to show how the daily life can be described as a fairly unified experience. The usually long histories of progressive decline with periods of acute poor health impacted many parts of daily life, from mobility, emotional wellbeing, performing usual activities, pain or discomfort and for some, becoming housebound through a combination of fear and physical limitations.

Just as Martin (2007) highlights, and is well argued by Foucault (1976) and Butler (2005), the establishment of the subject, such as I have also contributed to, often reflects broader cultural norms that influence our discourse and behaviour in a way that reinforces a dominant social order. Here I would like to focus on how research, particularly when there is a reliance on repetitive methods that focus on individual experience, can begin to establish a common sense of subject. This may be particularly so in an area like heart failure which is very poorly known or understood (Remme et al, 2005). This lack of knowledge about heart failure may reflect a lack of broader social reference points or identity, as it is an illness that is without the same identity as some conditions, for example cancer, which has many representations in the media, celebrity role models and a broad social story that people can connect to. In contrast, heart

failure has been an area of growing attention in health services research, where there is now a growing body of work that starts to build this sense of consensus about what it means to be a person with heart failure (Welstand, et al., 2009). Additionally, I suggest that this process continues to validate itself through using that growing sense of consensus to venture into developing typologies and theories, which are in turn tested using the same methods of focusing on individual experience. This provides an example of how research begins to collect and validate knowledge, which will become key normative values that are used as a basis for what we understand as the experience of people living with heart failure.

Under conditions of talking about something that cannot be mentioned, it may be dubious to form a model that includes the potential of avoidance, when clearly the avoidance behaviour applies to the researcher themselves. As I described in Chapter 2 (2.4.2) and earlier in this Chapter, Alan was a participant that I would have described as not knowing his diagnosis of heart failure. There was no interview data indicating that he knew his diagnosis, and we spent much time talking in euphemisms, despite later learning that he did know his diagnosis. In further efforts to talk to people about their feelings on dying without mentioning dying before the person might, I managed to ask people a range of questions about their views on their health or thoughts about the future. Clearly the assumptions that are made by leaving so much unspoken leave much ground for misunderstanding. It also seems to become more difficult to talk to people about dying when it is clearly an event that they might face in their near future, possibly as the greater immediacy may lead to professionals being more concerned about upsetting patients.

The potential for misunderstandings to develop under conditions where researchers are the ones exhibiting avoidance behaviour (and perhaps reasonably so), highlights the limitations in using such data to begin to theorise the experiences reported to us. The risk in developing such models too, is that people with heart failure come to be understood and 'improved' (such as by informing efforts to increasing medication compliance and self-management) through applying such models of their behaviours, without reflecting on the conditions in which we collect such data. This highlights the importance of ensuring a practice of reflexivity in research.

Here I have described two challenges, one being the way in which a growing synthesis of research can start to create norms, and secondly, how those norms come to be expressed in theories about people with heart failure that may in fact lead to the subjugation of people in relation to those norms. By subjugation, I am drawing on the influence of Foucault (1976, 1977) on my thinking, particularly in relation to the idea that how the knowledge of experience comes to be understood, may reflect dominant models of thinking, such as in relation to heart failure, the medical model. That knowledge of experience can then be used to also try to regulate or influence experience, including through encouraging people to comply with certain perspectives about their health and wellbeing. Self-management is a good example of how people are encouraged to self-regulate, based on knowledge that might privilege the medical model. Through this process, people with heart failure are encouraged to comply with norms, knowledge, expectations, which they may or may not agree with. In relation to heart failure, that knowledge faces difficulties, particularly in relation to the process of integrating qualitative studies, and how that includes and excludes, which is particularly pertinent given the potential I have outlined for this to lead to the development of norms and theories.

These theories build from individual stories and offer individualising perspectives about heart failure that become offered back as solutions to care problems (such as overcoming treatment burden). A consequence of defining norms is that by doing so we shape what is also non-normative, offering the basis from which we come to understand deviance from expected behaviour. In the case of mental health, this is called psychopathology (Martin, 2007), or in the case of heart failure we now have frameworks for pathologising people as non-compliant sick people with engagement issues and variable coping strategies (Gallacher et al, in press).

The process of amalgamating a range of studies, intensifies the lack of diversity in both the study populations, and the limitations of the research methods used. It also intensifies the broader values underlying the research, including the lack of sensitivity to the importance of that diversity, and the privileging of certain qualitative methods that are perceived to have greater objectivity or credibility in relation to medical model perspectives. In my view, this process then contributes to the development of norms that become increasingly homogeneous, and this is driven by the way the methods chosen are also a reflection of dominant biomedical perspectives in health research. Thus the norms become influenced by

both the limited populations used, and the biomedical values underpinning the selection of methods.

As an example of the role of constructed norms, we might consider again the case of Carol, who was seen as resisting help to manage treatment burden, even though it seemed to others that she would benefit from it. Carol also stood out as she seemed so unhappy. Carol was largely regarded as difficult by the staff caring for her, an opinion she equally expressed about the staff.

There's so much aggravation in this place it's unbelievable. (Carol)

Carol was sitting in bed on a multi-occupancy geriatric ward. She was on the end of the row talking loudly to me about how all the nurses were '*bitches*', and she added emphasis and volume should one of the nurses happen to pass in earshot. Her participation as a research participant in this, yet another qualitative research study, which feeds into this process of developing and testing norms, has an inadvertent potential to pathologise her based on deeply gendered, cultured, and social class obscuring, norms. Qualitative studies build a sense of knowledge, which is used to establish consensus and models or theories, these are then applied to further similarly generated studies, which confirm their validity and affirms the establishment of norms. However, those norms privilege particular representations of gender, ethnicity and social class, and those representations become influential to the norms through which individuals, like Carol, will be assessed.

The impact of socioeconomic circumstances on Carol's health became more visible from her surroundings than from her interview transcripts, but research that relies solely on transcripts can overlook the importance of that context in relation to talking about health. Carol did speak at length with me about the various concerns about money, aggressive behaviour in her community, and positioning for better accommodation on the estate, but did not directly relate this to her own deteriorating health. I began to notice that many of my visits to people's homes were to areas of the city that were socioeconomically disadvantaged. Carol lived in a part of the city where the life expectancy for women was 20 years less than the life expectancy for women in the most affluent area of the city (Scottish Government, 2010), and the council housing estate she lived on was well known as being an area of poverty and difficulties.

Carol's geriatrician did raise the importance of social class in how she and Carol may have different views on how to manage her treatment burden. Carol's geriatrician voiced her concern that there might be aspects of social class that influenced the rejection of offers help.

I don't know, it's difficult as well to know how much sort of social class factors and things come into this as well, I'm not sure they necessarily want a bunch of middle class do-gooders coming in and constantly interrupting their wee life and regime. (Carol's Geriatrician)

As I continued to move away from visiting individuals in hospitals and began to visit people in their homes, I began to feel that whilst it is important to understand the experience of heart failure through these common approaches to research, it is just as important to explore what such approaches do not help us to understand, and indeed to challenge the way such approaches lead to the perpetuation of seeing people with heart failure, individuals without considering their socioeconomic status.

A district nurse caring for Carol told me she liked working in that part of town, as the patients were less informed and therefore easier to manage than the last place she had worked (which was in an affluent part of town). This highlighted to me the need to find ways to explore heart failure that understands individual experience, but also challenges the way research may lead to the subjugation of people with heart failure, through the perpetuation of norms and expectations which may not always reflect the context of people's lives. This also means acknowledging my own role in building this body of knowledge, and that despite my best intentions, that work will likely be integrated into the next review of qualitative studies of heart failure and contribute to that process.

3.3 Summary

Finding ways to work that challenge how an analysis of individuals may form knowledge that might be used to also try to shape individuals experience, is a central challenge of this thesis. I had learnt a great deal from characterising daily life with heart failure, but saw myself as offering one point of view about this experience. I have cautioned against the use of generalisations or generation of theories that are based on individualizing analyses, and give the examples from my experience of Carol to highlight what important parts of her story could be left out of our understanding of daily life with heart failure if we rely on a limited range of methods for understanding experience. I have also attempted to make the point that as we move towards making the subject of the patient with heart failure, we can subject people like Carol to descriptions such as aggressive, painting a gruesome picture, resisting much needed help and non-compliant, against norms that have developed from the collective efforts of many researchers, including, despite my best intentions, the contribution of my own research too.

The challenge remains to make space to avoid subjugation, but I do not mean to imply that I feel have immunity from doing the same. If anything, this thesis tries to expose how I have at times participated in these processes myself, and find a variety of ways to reflect on how this happens. I have not explored in full detail how the processes of subjugation or individualizing may be defined from different theoretical perspectives. The aim of this thesis is to explore methods that broaden ways to think about experience, and allow space to consider the many processes that influence how individual experience might be understood. This also means exploring methods that show how people have agency in their experience, and at times agree with or resist the norms or expectations that may have emerged from research.

4 Doing Heart Failure: Performing the Subject

In the previous chapter I examined the experience of daily life with heart failure, exploring how people describe living with heart failure. I tried to create a context for understanding what it can be like to live with heart failure, but also made the case that broader thinking is required to avoid the risk of conducting, or replicating, research that reinforces cultured, gendered and class influenced norms. I established the case that norms, including those developed through research, can be used in ways that lead to subjugation of those we research, against those norms. This leaves the problem of finding ways to think about research that are less likely to be used against those we research. As Martin (2007) described, considering data in its broadest sense, and across contexts, is one way in which to create space to consider alternatives to subjection.

In this chapter I start to explore the many contexts that people with heart failure exist in. My goal in doing this is to start exploring ways we might move beyond just describing people as subjects, and onto a broader view of how experience is expressed in different settings. I think it is important to begin, however, with a descriptive account of the settings in which the idea of becoming a patient, become realised.

I then go on to draw on Butler (2000, 2005) as I am interested in the performative aspects of living with heart failure. There is a strong tradition of considering performance and performativity in sociology (Denzin, 2002; Goffman, 1978), which I have not explored in this thesis. My interest in focusing on Butler (2000, 2005), is because of the nature of resistance or compliance to norms, but also, because of the very close and particular focus on the specific use of language. I'm interested in exploring how we can broaden our dialogical relationship with research, both by moving closer into our data to consider the specific use of language (than we do with themes), and by looking to broader contexts (such as by considering epidemiological, cultural, and historical perspectives). Additionally, Butler's (2000) approach illustrates something of how norms are created, maintained and resisted, although such an approach has not been applied to the area of heart failure previously. In living with heart failure then, what does it mean to learn the norms of 'the patient', and indeed what does it

means to have 'heart failure' itself? In this chapter I will explore the use of performativity in relation to how it contributes to the qualitative methods used to explore heart failure, and how it may further our learning about what it means to be a patient living with heart failure.

4.1 The Settings of Heart Failure

I was not particularly comfortable in hospitals, particularly when it came time to venture from the day hospital, where my recruitment began and I had a known contact, and onto the wards. I would nervously try to identify who on the ward needed to give me permission to be there or uneasily put on plastic apron and gloves to visit people who were identified as being MRSA positive and therefore potentially infectious. I was very uncertain as to the rules and expectations of how I was meant to behave or perform in the various institutional settings. There were new relationships to negotiate with people, professionals and systems. It seemed apparent to everyone else who might be in charge on the ward, but I would tentatively try to read the signs about who to approach to talk with about my research for permission to approach a referred patient or how to access (let alone understand) medical notes. I had to learn how to gain the confidence of professionals who would facilitate access to patients. One day, later on in the study recruitment period, a nurse came up to me on an inpatient ward, where I was recruiting a patient. As I flicked through patient notes, wearing my official name badge, after negotiating access to the ward from the charge nurse, she asked me if I was the social worker. That was the day I knew I had made it into the institutional world of heart failure. I had absorbed how to behave, perform and conduct myself so I could be recognised as a legitimate participant in that setting.

Heart failure patients are located in many different settings, and the challenging work of recruiting patients into research studies happens in different ways for every study. When it came to heart failure, I had to learn quickly that there were many different institutions and services that interact with people as they live with times of good and bad health in relation to heart failure. The first setting I approached for recruiting patients was a geriatric hospital with an attached day hospital service. It was good relationships with a local geriatrician that lead me to start here and to recruit the first four patients, Allan, Frank, Linda and Carol, from this setting. The day hospital set the scene for these first interviews, where we sat with a cup of tea in a quiet clinical side room. The day hospital was a place that patients attended, usually for a

time-limited period, to follow up on issues post discharge. Patients sat around the room, sometimes chatting together, waiting to have medical checks or specialist input from a range of health professionals, such as physiotherapists, occupational therapists or a visit from their consultant. The day would include lunch, which was for some, like Frank, a social time and a highlight about attending this setting.

My conversations with Allan, Frank, Linda and Carol illustrated the many settings heart failure had led them to. Allan mostly received his care from the same set of health professionals, but between the rest of this group they had visited most of the hospital and emergency admission wards throughout the city. Even Allan had noted that before he started attending the day hospital he had managed to visit every hospital that was possible, with the exception, he noted with a wry smile and special emphasis, of the maternity services. The variable nature of heart failure led people in and out of many different places, moving to and from their homes and into brief (and not so brief) stays in hospital environments. During times of good health a range of primary care professionals, or a specialist nurse, might lead their care. Transitions to different settings however would lead to a new set of care provider relationships and priorities.

Attempting to identify new people with heart failure, as well as keep up with where Allan, Frank, Linda and Carol might be, led me into various institutions and communities, as I visited people in their home, hospitals, clinics and hospices, and followed their journeys in and out of those various settings. At times I even lost people around the various institutions, particularly Linda, and would learn to phone medical records departments, and sound official in order to find out which hospital and ward people were in, as I described in detail in the introduction. The variable pace of heart failure was played out over many different places. My initial feeling of ease at identifying Allan, Frank, Linda and Carol as participants for this research was soon surpassed by the complexities of their fluid movement from home to institutions and all the various inputs of care that complimented both places. The impact of living with heart failure led to new places that each person in this study would experience, or changes to the spaces they already knew well, like their own homes, through the influx of carers and other professional into those settings.

I was most comfortable visiting people in their own homes. In those settings I had a better sense of the social expectations, particularly in contrast to gaining access into medical settings.

Home was a place I could usually fit into comfortably and participants were very welcoming. It was also more informative to visit people in their homes, surrounded by what was important to them. In contrast, the small depersonalised spaces people occupy on hospital wards can illustrate less about their lives. Two particular participants, Fraser and Eric, sat and talked with me from their favourite spots at home, and both had photos of their deceased wives sitting close to them. Both talked to me about the impact of being widows on their lives in a way I doubt would have been raised in a different setting.

Professionals put much effort into ensuring people could be at home and for admissions to hospital to be reduced or prevented. There was often a shared goal that home is best, and the care provided by families was the preferred care, either for reasons of quality or cost. Extra support was offered to the home system to help prevent hospital admissions. Part of supporting the home system of care involved the introduction of services, such as putting to bed services, home helps, palliative care, volunteer befrienders, occupational therapists and nurses. Such services were an essential part of helping the home system to cope with the increasing needs of patients living with heart failure.

She's got a lot of social needs, but they're quite well addressed because she gets a lot of carers coming in, she's got aids in the house, she's got good family support. So she's actually quite lucky that she's got a lot of support and that's the only thing that's really keeping her going I think, you know, because she would never manage herself. (May's Heart Failure Nurse)

Accepting help with personal care, such as going to the toilet, dressing and washing, was difficult for many participants. Some of these tasks were supported by a putting to bed service, where a care assistant could come into the home and assist. However the service was not always able to come at a time that was appropriate, which left people with the option of having assistance getting to bed unusually early (for example 6 pm), or making do on their own or with a partner. Having to rely on a partner to assist with personal care could also be difficult, with some degree of discomfort about this shift in role, even in supportive relationships.

Many other participants were offered support and help to facilitate them being able to remain at home. For many, home started to transform with lifting equipment, commodes, stair lifts,

ramps, home helper, meals on wheels and visits from health professionals such as district nurses, who are based in the community. Home became a unit that needed support to ensure the aspiration of being able to stay at home could be realised and that included addressing this role and needs of the carer.

*Yes, try and look holistically at the situation and send him home, yes because that's the right thing for him, but say if there's anything else we can do to support the unit of them as a couple because yes, she needs support, and again I suppose ultimately it's in his interest to get her on board because otherwise if she is under strain it won't last.
(Frank's day hospital nurse)*

Allan lived alone with his dog and had a range of supports helping him to continue to live at home. He had contact with home helps, dog walkers, a gardener, meals on wheels, a pharmacist and a day hospital. Allan attended a day hospital on a regular and ongoing basis and had previously had a heart failure nurse specialist visiting him. The professionals involved in his care ensured he could continue to attend the day hospital, which was ordinarily a strictly short term service, on an ongoing basis, as they felt this was important for keeping him at home and reducing admissions to hospital.

So hopefully we feel that if we keep an eye on this, it prevents him coming in, or that we can give him the intervention sooner, or make his admission shorter. (Allan's Day Hospital Nurse)

Many professionals felt more services could be made available to people with heart failure that would help support the home system of care. This included increasing access to social support, palliative care, specialist nurses, respite for carers, sitting services and emotional support. There was a view that the physical part of heart failure was fairly well catered for, but the emotional needs for support could be much improved.

In terms of the hard facts of his heart failure, I think the current services are fine. It's just in terms of emotionally, I think we're meeting his physical needs but we're probably not meeting his psychological needs and we're probably not meeting the needs of supporting his wife as well as we could. (Frank's Consultant)

There were potential financial burdens of requiring extra help at home. Not being able to afford additional help placed a strain on people who were not able to perform their usual activities. Careful choices had to be made as to which essential services to invest in, and even once such a choice was made the care provided, such as home help, may not be particularly convenient. For Helen having a shower would cost £8 worth of carer help, which was expensive for her. Once deciding to have the shower, she would have to wait for long periods of times for the assistance to be available.

It would just be when they were able to come, and it would cost me £8 an hour. Now £8 an hour is a lot of money when you're on a pension and fair enough the £8 an hour I wouldn't have minded, if I was getting it when I wanted it, not just when they felt like you could have somebody. There are too many people on their books. (Helen)

People faced additional expenses for transport, diet, home help, personal care and personal alarms. Whilst there was a range of financial situations described in this study most people were living on low incomes, and in state housing. Few people were receiving state help for costs for care, but many talked about being assessed by social services as being only just over the threshold at which they would qualify for more assistance. Some people expressed anger that there was no government assistance to help them, after many years paying national insurance contributions.

Helen received a range of additional support to help her stay at home. This consisted of home helps, a volunteer befriender and a heart failure nurse specialist. The heart failure nurse specialist represented a bridge between the hospital setting and home. Based in the acute setting of the hospital, and working closely with cardiologists, these nurses provided a community based service by visiting people in their homes. The nurse would vary the amount of contact depending on how stable Helen's heart failure was, and saw her role as making up for a general lack of support from primary care services.

Helen didn't really feel she had that much support from the GP practice, and she sometimes finds it difficult to get the GP out, and things like that. She was a bit down, you know, so really that was one of the main reasons I started visiting her and

subsequent visits after that are determined by, you know, how's she's been you know. So if she goes through a period of stability then I maybe don't see her for a month, or six weeks. If she's unwell I start visiting her again. (Helen's Heart Failure Nurse)

Professionals and patients mostly shared the aspiration of being cared for at home. The idealised version of home was a place where you could rest in your own bed, be with your partner, see your family, be with loved pets, sit in your garden, eat what you liked and be yourself. However home was not always a nice place, and for Carol it was a place of interpersonal conflict. For others, like Helen, as described in Chapter 3, it was a place she was isolated in, and although comfortable, she described feeling lonely over long weekends where she wouldn't see another person between the home help leaving on Friday until she returned on Monday. People's homes slowly transformed, with additional help and inputs from carers and professionals. The home that people had could slowly be disrupted, changing the nature of the setting of home.

In contrast, hospital settings were very consistent and it was the person that may be disrupted in needing to adapt to the uncompromising conditions of hospital environments. Whilst I met Carol, in the hospital, she was being cared for in a number of settings or systems. This included her home and family, which primarily consisted of her husband Ray, frequent admissions to a local geriatric hospital, her GP, an occupational therapist, daily home help and the district nurse. This was a fairly usual arrangement of different carers and institutions, for most people with heart failure I met. When I first met Carol it was during one of her many admissions to hospital, when I introduced myself on the ward the charge nurse rolled her eyes and said 'good luck' as she pointed me in the direction of Carol's bed. As Carol told me about her experience of heart failure (although she didn't know this was what was wrong with her heart) and her care in the hospital, she was angry, sad, crying and shouting, as I described in Chapter 3. Carol was described as very hard work, challenging and needy. Professionals found her very difficult even though they could recognise her need for reassurance and care.

I think she has a pretty awful life and so I would be quite sympathetic to her and quite forgiving of her. I think it's a lot harder for the nurses who are having to answer the buzzer every two minutes, we've just taken you to the loo, what do you mean you need the loo again, we've just taken you, what do you mean you need me, look I have got

other people to look after. And I think they have a lot harder work to remain civil and patient and nice to her. (Carol's Consultant)

Managing the experience of hospital admissions was not unique to Carol. All participants had spent time on acute admissions. Alongside learning the logic of the institutional space there were rules about what merited an admission to hospital. For most these rules were based around the severity of symptoms, with many admissions being based around controlling the retention of fluid. The admission process was often the first point of contact with a hospital, and people described being queued up in admissions areas and directed like traffic to the right place or hospital.

Once a space was found for a person on a ward, they had to adapt to the social organisation of ward life, where you might be sharing a space that was organized along lines of a particular logic, be it by specialty (such as cardiology, general medicine or geriatrics), severity (admissions, intensive care) or gender. The rules around how to behave and when to be admitted the hospital were negotiated by people as they adjusted to how they were expected to behave as patients. These rules were not always clear, and May, despite her extensive experience in living with heart failure and her understanding of when she required admission to hospital, described a tension in coming into contact with a nurse who seemed to feel May was not acting as a patient was expected to act in the ward.

Another nurse said to me the last time I was in the hospital, you know you can't come in here whenever you want, I said I beg your pardon, I said I didn't ask to come in here I got told I had to come back to the hospital. And then (my daughter) went out to the desk to see how I was and she said who sent your mother in, she said the carer, she said oh the carers know more than what I know. So of course when (my daughter) went to the hospital with me she told the doctor and he was mad. (May)

Whilst used to living independently, people might find themselves living temporarily (and at times for a period of many weeks) in shared spaces with strangers. Some of those strangers would be medical staff wanting to do tests, or researchers like me, wanting to learn from their experience. With repeat admissions to hospital a feature of living with heart failure, the constant adjustment to shared hospital wards could be a challenge. Allan lived alone and

found the challenges of the shared ward environment difficult. In particular he found the generalist geriatric ward challenging due to sharing space with patients who might have conditions such as dementia.

RP: And what do you think of the ward?

Allan: Rubbish. Absolutely rubbish. And what made it worse is one particular man what was his name John he was away with the fairies. Oh I was in the (army) he says. He's eighty one year old. You can imagine how barmy he is.

Hospital admissions also posed particular issues for carers, where the potential respite from the home system of care could turn into daily trips across town to visit and provide additional care for their partner (such as providing additional food and doing laundry). Sometimes this was also at an additional expense for families.

Yes when he's in hospital it gives you a break in one way, that you don't have them twenty four hours, but you are going to the hospital every day. Your day is taken, part of your day is taken up going to see him in the hospital, but you don't have him twenty four hours. When they're home from hospital it's great they're home from hospital they're no longer in hospital so that's good, but they are with you twenty four hours. But with him going to the day hospital I have that time if I want to go anywhere, or do anything, or that I can go out while he's in the day hospital and come back for three o'clock. (Frank's wife)

In all of these settings, a person would be confronted with new relationships with various medical professionals, who often had an authoritative role. People needed to learn how to perform as patients in these settings, just as I also had to learn how to perform as a researcher. Even the home setting changed, particularly with the new dynamic of professionals coming into that setting. In the next section of this chapter, I explore how the identity of becoming a patient in those settings develops, particularly in relation to the role of performance.

4.2 Doing Heart Failure

Across the many different settings people may experience living with heart failure there is a sense of disruption, either to the setting (home), or how you might be expected to behave (such as in hospital). The idea that there is a sense of disruption highlights the way in which there are expectations, or norms (see Chapter 3, section 3.1), that define how people are meant to act as patients and carers living with heart failure. Heart failure is not associated with a strong social identity, and there appears to be little in the way of a definitive and public understanding of what it means to have heart failure, or to be a patient, or a carer in relation to the condition, but implicit norms remain. I became interested in how the performance of these norms occurs across those many different settings and contexts which offer spaces to perform those norms, or to disrupt them. Just as I had to learn the way to behave as a researcher in the hospital setting, and only by succeeding at this did I feel I would get the adequate access to notes and patients, how do people with heart failure learn how to perform as patients across different settings?

An explicit example of how heart failure is performed is found in a DVD called 'Living with Heart Failure', produced at the time of the research conducted for this thesis, by Chest Heart and Stroke Scotland, who I was working alongside with, to run a Heart Failure Patient Forum . The DVD had the aim of informing and supporting patients with heart failure. The DVD opens with an actor attempting to inflate the tyre of an old fashioned car with a hand pump. This research and the literature (Tayler & Ogden, 2005) show how the impaired pump is commonly used as a metaphor for the pump of the heart in heart failure. We go on in the DVD, with the presenter and a heart failure nurse specialist, to meet two characters living with heart failure, Tom and Maggie. Tom steps out of a very nice building, seems physically well, with a nice accent indicating a higher social class. He suggests going for nice walk and talk, and describes how he undertakes self management of his condition. He describes systematically monitoring symptoms such as swelling, complies with a medication regime, and gives the impression he is taking control of his heart failure. Maggie, in contrast, tends to her garden at the back of her nice bungalow, is also nicely spoken, and describes to the viewers how to prepare healthy food and how she draws on others for emotional support. Maggie and Tom combined illustrate what a heart failure patient might be, and draw on gendered norms of woman as

emotive/nurturing and man as objective/technological as they emotionally cope and take control respectively (Griffin, 1978). The heart failure DVD shows the acting out of the subject of the heart failure patient drawing on culture, gender and class norms.

Somehow I knew, as I watched it, that Tom and Maggie were likely to be actors, acting out a pre-determined script on what it is to have heart failure. Their performance is heavily consistent with medicalised ideas about compliance and self-management, and this performs a norm of the good patient. Part way through the DVD we cut to John, who looks very unwell. He is very breathless, has a working class accent and is less well spoken. He is shown from the shoulders up only, and somehow he seems less optimistic than those that are acting heart failure. He finds he cannot do much anymore, and worries if he does go for a walk, just how he will manage to make it back. We are focused in so closely on John, and one other real participant, we can only see them from the shoulders up. In contrast to the actors, the real people are viewed away from the context they might come from. In research too, we often take a view from the shoulders up, running the risk of obscuring from view information that is important to understanding experience.

Although the DVD illustrates the performance of heart failure in a fairly literal sense, it does illustrate the way in which norms are an acted, but understood, phenomena. I have already touched on how, as a researcher, I maintained an appearance of being consistent with norms about sexuality in conversation with participants. That was an example of explicitly deferring to the norms, or even performing a norm that would make me, and my account of myself, fit with the expectations and assumptions of those around me. In many ways it was not difficult to present myself in terms of the expected norms, as socially embedded norms as heterosexuality are explicit and easily, and sometimes essentially, presented to others. For Butler, gendered behaviour is not something that is inherent within us, but comes from conformity with, or resistance against gendered norms that surround us.

Drawing on Butler's (2000, 2005) analysis, I am interested in the performative aspects of living with heart failure. In particular, Butler's (2000) approach illustrates something of how norms are created, maintained and resisted. This is of interest to me in relation to exploring ways to conduct research that considers broader contexts, as explained in chapter three, section 3.2, of

this thesis. In living with heart failure then, what does it mean to learn the norms of 'the patient', and indeed what does it mean to have 'heart failure' itself?

Ray, Carol's husband and carer, wrote to me to explain what it meant to him to be a patient and a carer respectively, following my invitation for him to get in touch should he have more he wished to share. From his point of view 'the patient' needs help, reassurance, truth and belief in 'the carer', and 'the carer' needs to be kind, but moronic, patient, calm and in emotional control. From being Carol and Ray, they are now transformed into 'the patient' and 'the carer', phrases which are endlessly reiterated through the experience of heart failure, building the viable subject of patient and carer.

The Needs of the Patient

Due to my wife's condition she now requires 24hrs a day help and looking after.

1. She needs to be able to trust her helper to do what's right.
2. She needs constant reassurance that her helper will be by her side no matter what happens.
3. She needs to know the truth about her condition and accept the fact that things are far from good and live on a day to day basis.
4. As with both of us the knowledge that our last wishes will be carried out makes things a lot easier.

The Needs of the Carer

A carer has to be a mixture of a kind person and a mindless moron who at times has to switch off any feelings in order to do the job. A carer has to have:

1. An endless supply of patience and calmness
2. A firm belief that what he or she is doing is right.
3. Must be able to control and switch off their emotions on demand when dealing with certain requests and situations.

Ray

Ray lists the impossible ideal of what it is to be a carer. Just as with gender, it is an impossible idealised goal, that then can only be conformed to, or resisted, but not likely ever totally achieved. People living with heart failure come to accept, or negotiate, this identity of patient into their descriptions of themselves, and use it to distinguish a role in a setting, such as a hospital, that is different from other types of roles.

*I had never been in a hospital in my life, I had been in visiting, but never a patient.
(Maggie)*

What it means to be a patient is someone who is in ill health, has needs and is expected to behave in certain ways. In one example, Brian associates the idea of becoming a patient, as being in very ill health, and resists the idea that others are needed to help with basic tasks, resisting the very identity as patient as seriously unwell.

*Brian: Oh if I do anything out there as much as drop a thing on the floor, and try to pick it up I get ...oh I say come on I'm not as bad as all that yet.
RP: They make you behave do they?
Brian: Aye they treat me like a patient.*

Additionally, patients are the property of others, particularly the health professionals involved in their care. This is perhaps most obvious when patients are in institutions that reflect that authority, such as in a hospital, where the rules and expectations are known by professionals, and others, such as patients, or even me as a researcher new to that setting, have to find ways to learn how to conform with or resist expectations, as I discussed in the first part of this chapter. In these settings professionals have authority, from how a patient is expected to act, to whether they are to be admitted or discharged from that setting or not. This sense of authority is apparent in the discourses from professional describing patients as belonging to her/him. There were clearly benefits to being 'owned' by a professional, in that they may offer special care or privileges to their 'patient'.

Well I was very fond of him and we operate a roomed nurse down here, and I know I'm guilty of if they're my patient, they're my patient, which is awful (laughing). (Eric's Nurse)

Patients are not only ill and owned, but also no longer are reasonably expected to have control of themselves. However, as illustrated by this professional talking about May, they can be allowed to be in control, as and when the professional considered it acceptable. Again the language used by professionals, to describe patients, reinforce the professional authority in relation to defining expected behaviour.

I think May's main need is connection with her family you know and still feeling in control, May likes to be in control, and I would say that's probably the ultimate one of her ultimate goals is to maintain as much control for the patient as is possible, but also helping someone understand, you know how to kind of conserve energy, so that they can be in control for periods of the day, you know, completely, and she's good at that actually she's quite good at that. (May's Heart Failure Nurse)

Patients are also monitored for conforming to such norms, and some have described being called the 'miracle patient', or the 'star patient', for being particularly good patients. Being a patient was not always seen positively, and for Matthew he described negative behaviour as part of how it is selfish to be a patient.

So many people are praying for me, working for me and helping me and it's unfair and stupid to be so selfish because, being a patient can be very selfish. (Matthew)

Owning the patient means there are new claims to the conversations that might be had about that person, and with that person. Here Fraser's daughter talks of how the patient-doctor relationship exists to the exclusion of 'the carer', illustrating how defining the roles, such as illustrated by the role of 'the patient', leads to certain expectations about how those roles are expected to perform in relation to others. In those roles, the doctor-patient relationship, comes to define how knowledge will be exchanged. This shows how performativity starts to become an act of social control (Salazar-Sutil, 2008).

Yes, you don't want to be the one that's starting the conversations, because he's the patient, so it's really patient-doctor, and you are just listening to what the responses are. (Fraser's daughter)

The role of social control is further illustrated when patients come to be seen as numbers to be managed, as opposed to people living with an illness, and there being a certain responsibility to do that by the professional that owns them.

I don't think anybody should ever be discharged from the heart failure service. But it's impossible, you have to for the numbers to be manageable, and the issue we're sort of having now, is who takes on ownership of the patient once they're discharged. We currently write to their GP to say please review this lady in six months, but what would be interesting to see is how many patients have actually had that done. (Louise's Heart Failure Nurse)

Where 'I do' may be uttered on an altar, to bring into being what it is to be a husband or wife, likewise in relation to heart failure, authoritative utterances of 'the patient', are made repeatedly, and by those who have authority. That authority is demonstrated by the power vested in the clinician, and reinforced by the authority of the setting, such as a hospital. Slowly, people learn how to perform what it is to be a patient with heart failure, in those different settings.

When we explore the performativity of being a patient with heart failure, it begins to allow for thinking of resistance against the norms, or as Butler describes it and as I have mentioned earlier in this section, the idea of '*working the weakness in the norm*' (2000, page 114). June was particularly good at working the weakness and had a number of accounts of ways in which she had challenged expectations about behaving as 'the patient'. In this particular account, she describes being moved in the middle of the night, from ward to ward, and night after night. She decided that this was not reasonable behaviour on the part of the professionals caring for her and protested, loudly.

No they had put me I went into ward twenty six, there was no beds in the heart, so they put me in the waiting ward. Then they decided during the night at half past three in the

morning, to wake me up and take me downstairs right out through to another ward. Right out in the main bit, and right round and into, and I never said a word, I just did it. So the next night, half past three they woke me up again. They were going to put me into a side ward. Well I said to him, no indeed you are not. I said I'm trying to sleep and I'm really being harassed to death. I've not been feeling well and I'm not moving. She said, the staff nurse said, 'but', I said there's no buts if you're going to insist that you shift me get me a phone and I'll phone my husband and I'll be going home. (June)

During this same admission to hospital for June, there was a further confrontation. She challenged the staff on the ward about the care of a fellow patient. Having already established herself as not conforming to expected behaviour, we see the emergence of the threat of authority, in that the nurse threatens to report her. June does not even allow the nurse to say who she will report her to, not allowing the performative utterance of authority to even occur, although she is visited by her cardiologist to talk about her subversion of the norm of the well behaved patient, in the morning.

I said, 'and strip her bed and get a hot water bottle to put in. That old woman is frozen, and make sure that you wash her'. I said, I just told her straight, I said 'make sure that you wash her, she's soaking poor old soul'. She said, 'it's nothing to do with you', and I said 'you're very lucky that that's not my mother', I said, 'the whole hospital would have been upside down'. So she said 'we'll report you to the', I said, 'you can report me to who you like!' So they sent a cardiologist up to see me in the morning. (June)

The importance of the presence of authority in this account from June is that it adds legitimacy to the idea of drawing on the notion of performative utterances, which requires conditions of authority that can both reiterate and reinforce norms in order to enforce them. 'The patient' is a frequently uttered designation, requiring certain behaviours, illustrating particular relationships with authority (institutions and medical professionals), and ways in which social control can be imposed, or at least in the case of June, attempted, in order to control behaviour.

The level of authority that reinforces performative utterances is illustrated by the following account from Peter. Peter was waiting in a hospital admission area, due to an emergency

admission relating to his heart failure. He had an angina attack, and needed to use his prescribed spray to ease this attack. However he was physically unable to move, unable to get help easily, and when he did get help, he was treated very poorly. Peter's experience here, illustrates how that authority of medicine, can reinforce the utterances in powerful ways.

Peter: You're in the assessment where they put you into what I would describe as a cave. It's just one cubicle, there's no windows and a door into the passage, there's no alarm to call for help or anything.

RP: Right so you feel very sort of on your own in there.

Peter: So you're in there and I say to them what happens if I need, oh there's a passage outside, somebody will hear you just shout to them when they're passing. So I said to this young training nurse, I think she would be, that I had a pain in my chest and I could see my spray, but I couldn't reach it, so I asked her to pass it over. 'I will not', she says, 'I'll tell you when you can have your spray'. I said 'well that's not the instructions I got from (Dr B)'. I said 'I use the spray when the pain comes on and if it doesn't go away, I've to use it again, and if it still doesn't go away I'm supposed to call an ambulance'. So eventually she went over and got the spray so I took it out, 'oh no' she says 'I'll do it, that way I'll know you're getting the right amount'. So over she came, 'open your mouth, put your tongue up, that's it' she said. I said, 'what's that there?' The stuff went all over my cheek. 'I don't know what that is'. I said, 'well that's what should have gone under my tongue', she said 'what?' I said 'that's what should have gone under my tongue'.

RP: She sprayed it on your face?

Peter: Just missed my eye. I said 'I'll do it', 'no you won't' she says, 'I'll do it and then I'll know you're getting the right amount. So there you are', she says. I said, 'I'll need to do it again', 'why?', I said 'look', she said 'what's that?' I said 'the same as the one you did before'. I said 'that should have went under my tongue'. So then of course I had to wipe it before I got it in my eye and she put the top on this spray here she said, 'do it yourself' and she threw it at me. Fortunately it just hit me here, but it could have hit me in the face, and away she went, that's the honest truth.

I have tried to illustrate that through drawing on the idea of performative utterances, we can gain some insight into how we enact being 'the patient'. However, how do people 'do' heart

failure itself? For many, these words 'heart failure', mean the heart has literally failed, or stopped. When it comes to performing the illness of heart failure, the idea of your heart stopping, is not an accurate description. For many people in this research project they had not been informed that they had heart failure, and whilst I will reflect on this in later chapters, I think it is interesting to note here how the discrepancy between what the words heart failure might literally mean, and what it means to have the condition of heart failure, may have some role to play in how infrequently the diagnosis is shared with patients. The words heart failure themselves, lack the authority of performative utterances.

Brian: Your heart stopped and they said what happened to me was heart failure. Of course they didn't know then about the heart I think that was more or less the idea you know.

RP: Right but it just failed and that was that?

Brian: Oh aye just a case of he died of heart failure and that was it.

RP: So what were you thinking then when they first said the words heart failure did that give you a fright?

Brian: No not really because I knew I was still alive and that's what I said to them how do they call it that? She said I don't know why they call it that but it's been that way for a wee while now.

In this sense, the sharing of the words 'heart failure', may undermine the authority of the professionals and institutions that charged with the authority to say it. Perhaps this makes these words much more challenging for professionals to say.

4.3 Summary

By considering people with heart failure in relation to the Butler's (2000, 2005) ideas of performativity, we can take one step beyond individualising accounts, and consider the relationships between people with heart failure, the settings they find themselves in, and the professionals caring for them. Participants are shaped through strong messages about expectations of what it is to be a patient with heart failure, from the messages in the DVD about being proactive in self-care, to authoritative demands to behave as a good patient. These messages about how patients are expected to behave are not neutral, but rather

professionally driven and part of a process of social control. In relation to advancing a dialogical understanding of heart failure, considering these aspects of performativity is important for considering the audiences that patients may be talking to, when interviewed. When I succeed in being seen as the hospital social worker, do I then also risk being seen as one of the professionals that are part of the medical institutions when I interview people. This may in turn influence the accounts people offer to me, as being defined as a patient leads to conforming or resisting what it is to be, or perform, being a patient.

Despite the interesting insights we may explore through thinking about performative utterances, it still in some ways, to me, feels like taking a picture of the subject from the shoulders up. Butler (2005) highlights how the subject, the 'I', is always understood in relation to an other. In this case the other is me, the researcher, or even you, the reader. Butler (2005) also makes a compelling case that once we apply the idea that performative utterances reflect norms, wider social conditions and social control, it is impossible to be able to fully comprehend ourselves as a subject, let alone claim to understand an other. The other challenge of this approach for me, is that the agency of the individuals described can seem to become lost, as people become described as either resisting or conforming the norms that are set. It can be hard to describe how people participate in the construction of their own identity, rather than responding to forces that surround them. As put by Linda, this means we really have a limited grasp on any sense of truth, or how our participants participate in creating their realities.

Mind you I don't know if I've told you everything or if it's true that what I'm saying is true. (Linda)

However, whilst I think such approaches do offer very important insights, I would like to go on to explore further positions also. In doing this I wish to continue my journey of exploring the way we understand 'the subject', and think about who or what else may also be in our picture of heart failure. I think Butler (2000, 2005) can help us explore interesting aspects of how we create and maintain norms in heart failure, but what we do with that understanding, in my view, becomes futile if we commit to a context of total relativism, particularly as it restricts what we can do with those insights to further understand or improve what it is like to live with heart failure.

5 From Subjects to Objects: The Symptoms and Causes of Heart Failure

The starting place for this thesis was considering daily life with heart failure in Chapter 3. In that chapter I argued that by describing experience, research had the potential to transform people with heart failure, into subjects that can be categorised and theorised. I argued that such a process can lead to research developing, and then perpetuating certain norms about what it is to be a person living with heart failure. Such conditions can lead to people being understood or judged alongside those norms, which can lead to expectations or practices that may not be in the best interests of people with heart failure themselves. I have been developing an argument about how to undertake research that opens up spaces to explore experience without subjecting people to certain expectations about what it is to be a person, or patient, with heart failure. In that process I explored the work of Butler (2000, 2005) and considered how heart failure might be performed and the dynamics of social control that patients are embedded in.

In this chapter I focus on the role of symptoms and perceived causes of heart failure. Here I will draw on Foucault (1977) to argue that whilst research can transform people with heart failure into subjects, the role of symptoms in heart failure transforms subjects into objects. This transforms people into objects to be studied, managed, changed or normalised.

'... the socio-medical sciences do not find but invent the objects of their investigation, and therefore instead of being appendages to power the socio-medical sciences are in fact, its very essence' (Butchart, 1997, page 102).

I will focus on how people with heart failure and professionals describe heart failure. In doing this I focus on different discourses of symptoms and causes of heart failure, how that impacts relationships, and how it relates to the management of the condition.

5.1 A Collection of Symptoms and Self-management

Heart failure was mostly described to me, by patients and professionals, by the collection of symptoms it entails, which include breathlessness, oedema, tiredness, difficulty sleeping, nausea, falling asleep and pain. Breathlessness might lead to feelings of gasping for air or a sensation of drowning in the fluid on the lungs when trying to breathe. Oedema was also particularly common with a build up of fluid in different parts of the body including the legs, scrotum, belly and ankles. This build up of fluid could be quite shocking as parts of the body became unrecognizable, at times swelling to the point where liquid would bead on the outside of the body. People living with heart failure tended to find colloquial ways to describe these symptoms, such as Allan, who described his legs as swollen to the size of elephant's. Professionals, like Allan's nurse, tended to use a range of terms to describe such symptoms, such as, a faulty pump, a weak muscles, in a 'wet state', needing to be 'dried out' and floppy muscles. In this way professionals use these descriptions of symptoms to offer a biological description of the individual and their heart failure.

The severity of the symptoms of heart failure varied, with a fluctuating experience of improvement and decline, in the severity and impact of these symptoms on daily life. For some their physical condition meant their daily activities had become severely restricted, with a loss of ability to do basic tasks within the home. Others described the loss of independence outside of the home too, relying on other people to assist with doing shopping or going into town. This loss of independence led to feelings of frustration or resignation in living with such restrictions. May felt this loss of independence had transformed her from having a life, into feeling she was just existing, not living.

I said to myself, well I can't get out, I can't gallivant, I can't get a nice pair of shoes on, I can't get dressed up. To me this is not living, this is existing. (May)

This research was conducted longitudinally, and my conversations with Louise in particular reflect the process of her symptom-based discourse developing. When I met Louise, she was just starting to learn more about what the problem was with her heart and was trying to make sense of how her heart was damaged and how that might relate to her breathlessness. Louise described how she was told by her doctor that there was fluid over her heart. At this time

Louise was starting to shape the story of her heart failure, keying together information from the medical professionals involved in her care to shape the causes and symptoms of her condition.

It was a Sunday. I went down, the sun was shining and I said oh come on son I'll take you down the stairs. So I took him down to the bottom of the stairs, and he went out to the back green and I was standing at the front door and (my neighbour) lives across in the top flat came down to go in her car, and she waved at me and then she came across and her words was, what the hell are you doing standing there? And I said, I came down just to get a mouthful of fresh air, get up that bloody stair she says, and plonked me here, where's your doctors? I said there on the mantle piece, right, the next thing I knew she's on the blower to emergencies and all the rest of it then the next thing I knew the paramedic was here with a doctor... I was purple seemingly, I was blue (Louise)

What is heart failure?

This is a rather alarming term that is used to describe the signs and symptoms, which occur when the heart is less efficient at pumping blood around the body. This can be at rest and on exertion. It results from any heart condition that reduces the ability of the heart to act as a pump. When damage occurs the heart uses up some of its reserve normally used only on exercise, and so symptoms can come on with very little exertion.

Causes of heart failure

- coronary artery disease
- a heart attack
- long standing high blood pressure
- heart valve disease
- lung problems, such as emphysema
- pulmonary embolism
- specific heart muscle disease, such as cardiomyopathy
- anaemia
- an overactive thyroid gland
- heart rhythm problems
- alcohol problems

Figure 3: Living with Heart Failure, published by Chest Heart and Stroke Scotland

Louise was given information from her heart failure nurse specialist nurse, including information from a local charitable organization that offered a definition of what heart failure is and its causes. The information included a booklet from Chest, Heart and Stroke Scotland describing what heart failure is, and its causes, see Figure 3.

To me, the contrast in Louise's description of heart failure and that of the information provided to her by a health professional reflects the introduction of a discourse of medically defined symptoms into her account. Her initial story is quite eventful, turning blue, becoming breathless and being rushed to hospital where she was told there was fluid on her heart. In contrast the professional information described heart failure as a collection of "signs and symptoms" that the heart is not working well, and provides examples about what might cause such problems, for example coronary artery disease. As I visited people up to three times over six months, I noticed how the symptoms-orientated discourses became well developed, almost gaining a rehearsed quality, as people became more familiar with the surveillance and self-management of their symptoms suggested by their professional. At each visit, the medical discourse around symptoms was quite static, told and retold to me in ways that were consistent. In contrast, the more personal and non-medical stories of what people felt their heart failure meant to them, took longer to be shared, and it is those accounts that emerged later on in my visits with people. Those accounts were often conflicting discourses to the medically-orientated symptoms discourses, perhaps indicating how people both integrate and resist different discourses in relation to their own experience. I will next go on to explore the role of surveillance and management, before returning to revisit Louise and considering how alternative discourses also develop that resist the medically influenced idea of symptoms.

For me, not only did people with heart failure become subjects through research (see Chapter 3.2), but the focus on symptoms went further, and discourses then became more about depersonalised objects. The first findings of this thesis considered how research can develop norms that can then serve to subjugate people with heart failure, which relates well to Foucault's analysis of power-knowledge (1977).

Whilst heart failure often signalled restrictions to activities and independence it also brought with it a range of new activities in relation to the constant observation, description and

monitoring of the symptoms of heart failure. Patients would learn and use a range of words to describe symptoms and may even come to describe themselves as a collection of symptoms. This transition from person to a collection of symptoms is reinforced by the way in which people may be encouraged to monitor their symptoms, along with following clear guidance about when changes in symptoms should be reported to their health professional. The people receiving care from specialist nurses were encouraged to engage with symptom monitoring the most explicitly.

Foucault's (1977) argues that using individualisation of the subject, and self-regulation, against the broader norms or social expectations that knowledge-power influence, lead to compliance with expectations and norms. The process of individualisation is achieved through objectification (Hook, 2004), and I argue here that discourses focusing on symptoms can lead to such an objectification, and self-regulation.

These rules and reminders in Figure 4 were given by the Heart Failure Nurses to those who were referred to their service, which is a specific subset of people with heart failure. Those who did not have a specialist nurse were less likely to receive this information about self-management. Alongside the rules and routines of self-management are other regular occurrences in daily life with heart failure, such as attending regular cardiology clinics, regular visits with the GP, blood tests, renewing prescriptions and managing the flow of associated health care professionals.

Daily life becomes punctuated with being weighed, reducing salt intake, taking medications, monitoring fluid intake and checking for swelling. Whilst weighing was a usual way to check for fluid retention, Peter also had his own test of how easily he could feel his leg bone.

RP: Right and do you keep a track of your weight kind of thing?

Peter: I check it maybe not every day but twice or thrice a week under (my heart failure nurse's) orders.

RP: Right she's got you checking your weight yes?

Peter: She said to do it every day, but I don't do it every day I was doing it once a week, oh no no she says you can swell up in no time at all you see, you swell up ankles and everything.

RP: Right so that's checking you're not getting fluid with the weighing?

Peter: Yes. This bone here that's what I go by if I'm swelling up this one's not just quite as bad as this one. I can't feel that bone at all.

HOW ARE YOU FEELING?

Has your weight increased by 2 pounds today?

(If yes, then observe tomorrow and if another weight gain phone your nurse.)

Have you put on 3lbs over a week?

(then phone your nurse)

Did you awaken last night short of breath?

Did you need extra pillows to sleep with last night?

Are you feeling more short of breath than normal?

Are your ankles or feet swollen?

Does your stomach feel bloated?

(If you answered yes to 2 questions or more, phone your nurse.)

REMINDERS

Are you taking your medication?

Are you reducing your salt intake?

Did you exercise yesterday?

Has your appetite decreased?

Are you more tired than usual?

(If you have any concerns or questions phone your nurse.)

Figure 4: How are you feeling? Heart Failure Nurse Service Patient Information Leaflet.

Power works in ways that produce knowledge, that increase the ability to govern individuals (Hook, 2004). As I will discuss in Chapter 6, in the case of heart failure the power dynamics and

complexities illustrate the role of power in influencing how a diagnosis may not be shared, including how professionals wait for signals from patients that they would like to know more about a condition they do not know that they have. This may contribute, along with the uncertainty about defining heart failure, to a focus on discourses about symptoms, rather than talking about heart failure as a condition itself, as experienced by a person. In contrast to being located in people, heart failure is now evident in swollen legs, scrotum, belly and ankles. People with heart failure become, through discourses, about bits of fluid to be monitored, controlled and managed.

Whilst not everyone was clear about why they needed to perform these activities, regular blood tests, checkups and regular weighing were encouraged as a way to monitor heart failure. In this way people became increasingly described as a physical system which can be controlled, balanced and maintained in a 'dry state' through taking actions to ensure the bodily system wasn't too wet or too dry, or being compromised in relation to cardiac versus renal function.

The main things we probably feel are, we're keeping an eye on his weight, his shortness of breath, his renal functions sort of check his bloods and things because he is an end stage cardiac failure, it's tipping the balance between his renal failure and his cardiac failure. You give him too much diuretics he goes into bad renal failure, if you don't give him enough he gets a bubbly chest and short of breath on exertion. (Allan's Day Hospital Nurse)

Being able to successfully undertake these activities of self-management was seen as important by some of the participants in this study, a finding which is also reflected in the literature (Rodriguez et al., 2008). In the chapter describing performing heart failure, I also discussed how successful self-management was performed in a local heart failure DVD as part of creating discourse around performing the role of the patient. Professionals encourage self-management as being important to living well with heart failure. However it has been pointed out, in the literature, that self-management has specific, professionally defined parameters also. Leventhal et al (2005), define compliance with self-management as '*the patient's informed free choice of behaviours selected from those recommended by the healthcare provider*' (page 299), with professional responsibility to provide knowledge, skills and

motivation and patient responsibility for gaining skills, implementing the advice and seeking help when required.

The combination of individualisation, objectification and surveillance leads to normalisation, which is a state of being free of irregularities (Hook, 2004). In relation to heart failure this translates to the development of regular, predictable and manageable patients. This goal of normalisation is one that is supported by internal self-regulation but reinforced by the role of professional power, such as medical experts (Hook, 2004). Symptoms become a key focus in heart failure, as something to be studied, objectified and self-regulated.

Whilst people were encouraged to develop a discourse of symptoms and self-management, this had certain limitations or parameters. Symptoms were prioritised or considered important, mainly from the point of view of the professionals providing care. Frank had heart failure along with a range of other problems, including forgetfulness and impaired mobility. Frank gave serious consideration to all of the symptoms he observed, and hoped with enthusiasm that the professionals providing his care would use this information and be able to improve his health. I was visiting Frank in a day hospital setting to do a follow up interview with him. On this particular day he had been requesting a CT scan, which was felt to be unnecessary by the staff there.

Yes, he felt he needed a CT scan of his head. I didn't quite ask him why, I probably should have asked him, why did he think that he should have that. The medical staff felt that that wasn't required at all. (Frank's Day Hospital Nurse)

When I first met Frank his level of forgetfulness made me check his notes for any indication of impairment that would compromise his ability to provide informed consent. On his medical record he was identified as having vascular dementia, which he had not been made aware of. I had wondered if concern about forgetfulness was why Frank was asking for a CT scan and would seem, to me, a reasonable extension of his making sense of and monitoring a range of physical symptoms. I asked Frank why he wanted a brain scan and he told me about his experience as an inpatient at a psychiatric hospital after the war, for what was called epilepsy. He said that one day a psychiatrist told him he had two choices, one was to continue to be as he was, in which case he was going to lock him up on the secure ward permanently, or he could

decide to get on with it and go home and be with his family. He said his epilepsy has cleared up after that ultimatum, but he was always left wondering about his brain. He also said he has noticed he was becoming increasingly forgetful and wondered if this was related to what he described as this period of epilepsy.

Frank's monitoring of his symptoms and his hope for treatment of all of his symptoms continued to grow further beyond the parameters of what might be considered relevant by those around him. Frank was described as becoming obsessed with the idea that stem cell therapies could offer him hope in relation to his heart. His persistent requests to be given stem cell therapy were received with increasing frustration by the professionals involved in his care. He had been actively banned by his nurse and geriatrician from bringing in any further media cuttings about the topic and was discouraged from talking about it.

I think he doesn't know an awful lot about it and I think he's quite unrealistic about it and I think a lot of the medical staff have tried to tell him lots of things about it but he only hears what he wants to hear, he's fixated on it, he thinks he could have this stem cells and this would make him better and a lot happier. (Frank's Consultant)

Frank's account offered an increasing challenge to the professionals around him. As he was encouraged to engage with a discourse of heart failure symptoms, he encouraged the medical professionals involved in his care to continue their attention to other symptoms, but ones that were not considered relevant to heart failure self-management, such as his interest in stem cell therapies and his desire for a CT scan. The professionals involved in Frank's care appeared to me to be very caring and interested in their patients. However, the individualising and objectifying discourses of symptoms provided ways to depersonalise Frank's concerns and define them as irrelevant, and experience Frank as a nuisance. The objectifying discourses of symptoms influence both people living with heart failure and the professionals they receive care from.

Professionals have fewer limitations on the use of describing people in relation to symptoms and the reduction of people or patients to a collection of symptoms was used as a way to ration services. Frank was meant to monitor the symptoms that were defined as important by the professionals involved in his care, not the symptoms he considered important. In this sense

a patient becomes a collection of particular and professionally chosen symptoms, from which a rationale can be given for resource allocation. For Carol, her heart failure did not include poor left ventricular function, which then excluded her from receiving care from a heart failure nurse specialist, despite being described by professionals as having many complex and diverse needs which could be better supported with input from a specialist nurse.

She is not eligible for the heart failure nurse service because again on echo her heart muscle looks not too bad. She has valve disease I think is the main reason why she goes into heart failure, but the muscle is reasonable and so she is not eligible for a whole lot of the services which is a real shame. (Carol's Consultant)

Drawing on a discourse of symptoms, can influence the allocation of resources and planning of services. The ambiguity of the diagnosis of heart failure as a collection of symptoms without clear diagnostic criteria perhaps contributes to a focus on symptoms. Developing an account of excluding left ventricles from services, rather than individual patients or people, or groups of people or patients, transforms patients into symptoms to be managed through allocation of different types of care. In relation to this particular example, left ventricular dysfunction is also more often recorded in men than in women, introducing a gendered dimension to the allocation of services. Symptoms create a discourse that can be used to develop manageable criteria and depersonalize the issues of allocating resources. This gender disparity was the most visible to me one day at a Heart Failure Patient Forum, which as I mention in the Methods Chapter, was a user group I had helped to establish. One day we asked all the carers to go to a different room, and the people with heart failure to stay seated. There were around 50 people at the meeting. At our request, just about every woman in the room got up and left to the carers room. Of those left, there were only two or three women with heart failure in the room. We had not been aware that the heart failure forum was primarily being attended by male patients up until that moment. With left ventricular dysfunction being the entry criteria for the heart failure nurse service, who was hosting the forum, this was perhaps a very stark reminder of the gendered nature of heart failure.

5.2 Broken Hearts and the Heart Broken

It was my experience of interviewing Louise about living with heart failure that made me particularly interested in the role of discourses about causes of heart failure. I met Louise very early on in her experience of living with heart failure, I met her before she knew she had heart failure and after she had been told about her diagnosis. I received a phone message from the cardiology specialist registrar who had been helping me with recruitment into the study. He told me a patient had agreed to talk to me about taking part in the study and he hoped it just might cheer her up to meet me. I went into the general medical ward where Louise had been admitted to give her information about the study. Louise was sitting by herself in a chair beside her bed in the shared room of four. I introduced myself to Louise and as soon as she heard my New Zealand accent she started to cry. In between moments of tears and attempts to regain her composure, Louise told me of how she was meant to be on a flight to New Zealand that very day. A few days earlier she had become breathless, very unwell and had an emergency admission to hospital. Hearing my voice seemed to only highlight the trip of a lifetime she had not been able to make, and she was bitterly disappointed at not being able to make the journey. I sat and talked with Louise for a while on the ward. She felt tired and down and was looking forward to being discharged.

In the hospital Louise was told she had had a heart attack and had fluid on her lungs, which was causing her to be breathless. On my first visit with Louise at her home, this was all she knew about her heart problem. She knew that she now had a lot of medication she needed to take which related to her heart, but she wasn't all that clear about why. Louise was waiting for her first visit from a Heart Failure Nurse Specialist and hoped this nurse might be able to tell her more about what was wrong with her heart. Louise felt that knowing more would offer reassurance about her health, even though she was concerned about overcoming the barrier of the medical terms used to explain heart failure.

You know I do really I do I think if they would say well you're heart's stopped or whatever if it was in plain English then the people would understand more. (Louise)

There was a wide range of understandings and misunderstandings about what was the cause of heart difficulties for people in this study. Some people knew quite detailed information about the parts of the heart and how they were damaged.

I'm deteriorating due to an enlarged heart, and the left ventricle is bigger than it should be. And if you want to know the whole lot an aorta problem....So everything's working against me. (Alan)

Many people did not know their diagnosis of heart failure, and the most likely reason for knowing the diagnosis of heart failure appeared to be the involvement of the specialist heart failure nurse in providing care to an individual, including making sure they understood their diagnosis.

Brian: She's very nice, she's very what do you call it interested in it all. She tells you the whole thing she had pamphlets showing me my heart, well not my heart but a heart.

RP: Yes.

Brian: And how the one heart is the normal size and she said that's your heart on the other side she said, look how it's enlarged and seemingly one part of the heart extends itself.

RP: Oh right.

Brian: And it blocks the other bit of the heart that's why you get the heart sort of ...

RP: Right.

Brian: And then all the valves at the top of the heart instead of just taking their time they all just wobble around and this is what caused this feeling of you get anxious about it.

RP: A bit breathless?

Brian: I wouldn't say pain but you get that sort of feeling at times and then it just drifts away.

RP: So you get a funny feeling in your chest?

Brian: A chattering sort of feeling you know that's why they've given me this nerve tablet they think that might help.

Those who did not have a specialist nurse were unlikely to know they had been given a diagnosis of heart failure, and some, like Carol, were unsure if their health problems were due to their heart at all.

RP: What has the doctor said about your heart?

Carol: I don't know nothing about it.

RP: Really just that you've had some trouble with it in the past?

Carol: I don't know, I don't even feel that I've got anything wrong with the heart.

For others, who weren't clear about their condition there was a sense that perhaps they had recovered from their heart problem, despite the incurable nature of heart failure.

They said one side was different from the other it wasn't doing its job or something...

It's alright now. (Anne)

I heard many such accounts about the causes of heart failure, and over time they illustrated how discourses about the causes of heart failure emerged as being highly individualised and objectifying, with its focus on the organ of the heart. As illustrated in the next chapter on relationships and sharing of knowledge, there was a complex negotiation between people with heart failure and professionals as to whether or not they were told their diagnosis and prognosis. The uncertainty of this process of information disclosure is reflected in these accounts too, with some feeling that their problems had now passed. As I met with people up to three times, the medicalised, biological explanations tended to clarify and start to achieve a certain rehearsed quality.

I found it useful to draw on Foucault (1977) in thinking about the discourses about causes of heart failure, and for me, these discourses play an essential role in individualising the experience of developing heart failure, through providing highly individualised causal explanations about the condition. Such discourses are reinforced with the authority of medicine and evidence, already discussed in this chapter, explored in Chapter 4 through considering performance, and argued by Hook as essential in contributing to the power-knowledge process of objectifying (Hook, 2004). For Smith (1999) however, Foucault's focus on discourse is itself limiting in terms of understanding subjectivity as only ever discursively

produced, and that does not allow for alternative views of how knowledge and power are produced apart from that of individualistic subjectivities located in non-authorial discourses (Smith, 1999). The problem is that whilst Foucault's emphasis on discourse offers interesting insights into the process of the individualisation of heart failure, such an analysis continues to locate the analysis at an individual level, limiting the potential for considering non-individualising alternatives.

I suggest that it is worthwhile to complement Foucault's approach by drawing on the work of Bakhtin (Bakhtin, 1981; Holquist, 1990), as outlined in Chapter 2, section 4. In contrast to Foucault, by drawing on Bakhtin, I would argue there is greater potential to consider what is not always explicitly apparent in discourse, but influential to how discourse is created and used. Regardless of how accurately a person understood their diagnosis and prognosis of heart failure, there was a prevailing sense that science and medicine spoke with an authority about the heart, that evoked Bakhtin's notion of the superaddressee (Holquist, 1990; Hook, 2004; Smith, 1999). Foucault's sees discourse is as something that individuals participate in, and therefore also reproduce or perpetuate (1977). In contrast, Bakhtin describes the role of dialogism, which draws on the way in which speech, or utterance, has an audience. That audience includes the addressee, or the intended listener such as me as the researcher, but also the superaddressee, being a broader audience, such as science, God, or medicine (Holquist, 1990; Hook, 2004). This broader audience is evident in Louise's description of what was wrong with her heart, as she describes medicine and science as an omnipotent 'they'.

Louise: I wasn't bothering about anybody and all I wanted to do was to get better but now I want to know what my limitations are. What caused it is more all they've said to me well you know you were full of fluid.

RP: Right.

Louise: And the fluid went over your heart.

RP: Okay.

Louise: But that's all I was told or the fluid interfered with your heart something like that, but other than that I don't know.

The authority implied in evoking medicine as a super-addressee contributes to the transition from person to patient, as a new dominant knowledge offers a confusing and complicated

description of heart failure. Ironically, medicine itself is not able to define heart failure despite its influence on how people come to understand themselves as patients, and their hearts as failing.

There were indications, though, of people existing in a dialogical tension with the medicine super-addressee. With Louise, she had developed heart failure quite suddenly and was initially very surprised to learn her difficulties were caused by heart failure. Louise provided an account of herself as previously being very healthy and able to overcome her difficulties through sheer determination not to give in to the illness of heart failure.

RP: You are. What do you think has really helped you get back on the mend?

Louise: Sheer determination.

RP: Right.

Louise: Sheer determination.

RP: You had a determined look in your eyes when you said that too (laughing).

Louise: Plus the tablets I mean I couldn't have done without the tablets.

RP: Right sure but it's really come from being determined?

Louise: Oh aye I'll not let this get the better of me.

RP: Right.

Louise: I've always been like that of course a very determined person.

However the focus of this 'sheer determination' was not just in the direction of the illness, and her new status as the patient, but she spoke of determination to battle 'them' even as 'they' have told her that she will not get better, but remain in the status of patient for the rest of her life.

Oh aye you need that because I could have lay down and said oh I'm finished which I've seen a lot of people doing, I'm finished oh I'm never going to get better, they've told me this and they've told me that, no me, I'll battle them. (Louise)

Further, Louise reflected on having cast the super-addressee of medicine in the role of having a part to play in her being unwell, as she wondered 'what they have done to me' when she initially became unwell. As she began to feel better, and perhaps too as her indoctrination into

the daily routines of being a heart failure patient became more acceptable, she had more questions to ask ‘them’ about what was her future, including what dangers she was facing.

Louise: I’m feeling better I’m getting inquisitive.

RP: Oh right.

Louise: Of what all has happened to me you know before this I was too interested in I’m never going to get better, what have they done to me, why has this happened to me?

Now that I have got rid of all the fluid I mean you wouldn’t know my legs now, I’ve got rid of all the fluid now and I’m feeling better but what are the dangers?

Louise’s account reveals a tension between communicating with medicine reflecting a dialogical process or tension between the person and the patient, as a new form of powerful knowledge becomes part of this significant life transformation. Medicine forms the battleground, as she prepares to fight them, as the source of reassurance and knowledge about what to expect as a patient living with heart failure. Just as Louise engages in a dialogical sense making with science, she also engaged in the discourses of the social or emotional heart.

These social or emotional stories were the ones more likely to be told when the voice recorder is off, or later in my subsequent visits to people. Broken hearts were surrounded by non-verbal data, such as the photographs that sit beside the bereaved and keep them company. I met with people over a period of six months. Over this time there was little development or change to the medicalised and symptom based discourses people offered to me, but as we spent time together space emerged in which other causal stories and discourses began to emerge.

Discourses that reflected a medicalised version of the heart described heart failure as being caused by a long history of heart problems, such as angina or heart attacks, which have slowly caused the muscles of the heart to weaken in a way that cannot be repaired. People offered other accounts, of having lived through burden, loss, grief, exclusion and abuse as alternative factors contributing to the breaking of hearts. Formal texts are unlikely to begin with the statement, heart failure is a socioeconomic disorder, exacerbated by experiences of loss, grief, burden or stress. However there is evidence that all of these socio-emotional explanations are validated by medical literature, as the relationship between stress and its effect on cardiac

health has been widely established (Everson-Rose & Lewis, 2005). So why do these discourses present in a way that competes?

Throughout this chapter I have drawn on Foucault to show how discourses individualise and objectify people with heart failure, and this might be associated with the need to regulate and prioritise the provision of care. Smith draws on Bakhtin to argue for a similar analysis of ruling relations, where broader institutional needs influence accounts of everyday experience (Smith, 1999, 2005).

As I have illustrated, heart failure is mostly characterised by professionals as a failure of the heart to work efficiently and the cause of this relates to long term physical health problems, mainly in relation to different coronary problems. What would medicine make of different literature, say if I was to adapt the materials given to people living with heart failure to reflect the wider knowledge regarding the collective experience and the social determinants of health?

What is heart failure?

This is a rather alarming term that is used to describe the signs and symptoms, which occur when the heart is less efficient at pumping blood around the body. It isn't a clearly defined illness, rather a collection of symptoms that you will now need to learn and monitor to maintain your health, if that is what you want.

Causes of heart failure

- coronary artery disease
- a heart attack
- A range of contributing long standing physical health problems, such as overactive thyroid glands and anemia
- stress and strain from life's burdens
- heartbreak and loss
- social conditions and material wealth

Figure 5: An alternative definition of heart failure.

On my second visit with Louise she was reflecting that her heart condition had been aggravated by the stress and strain of her recent dealings with a lawyer as she was in the process of buying

her council owned flat. She had found the process stressful as it was something she wasn't familiar with and the only other time she had been in contact with a lawyer it was because of having an accident.

With the strain and stress, because I mean I had never known a, well once I met a lawyer, and that was when I had the accident on the bus. But when you go to a lawyer to see about buying a house, or anything like that, I never had anything like that before you know, and at my age you know it was a strain. (Louise)

For some people their conversations about their hearts began to broaden to talking about their emotional and social hearts, and not just the physical heart. These broader stories only emerged as I spent time with people and were told alongside the sometimes contrary medicalised discourses of what causes heart failure.

Brian talked about heart failure as one of the many nasty knocks he had experienced in his life, including a number of times when he almost died. This was similar to other older men in the study who had served time in the army during the Second World War.

Brian: I've had quite a few nasty knocks during my life.

RP: Yes haven't you?

Brian: I had a bad time just I went over on D Day, I was doing other things for by, but I went over on D Day and I lasted twenty seven days.

RP: Right.

Brian: So it was all my legs that got it, well not all my leg ?

RP: Oh right you've got a little mark there.

Brian: My dimple (laughing).

RP: Yes your dimple yes.

Brian: I had that and another hit my helmet which gave me a nasty head it didn't penetrate you know.

RP: Sounds like you were a bit lucky there.

Brian: I was very lucky, there was one hit the rifle, the rifle was shattered seemingly but I didn't know that I was told later on but it must have just come straight up and that was it, I got it in the hand but not very much in my hand.

Brian talked about these experiences of facing death in the context of coming to terms with and facing heart failure. Brian also talked about his experience of caring for his wife who had dementia and reflected how the burden had seemed to contribute to deterioration in his health. Over years he had become her main carer as she remained at their home. When it became too much of a struggle Brian reluctantly agreed that Barbara should move into a nursing home. It was only days following her admission to the home when he suffered a stroke.

My wife had been taken into the nursing home on the Friday and I went up to the window there and I had a duster in my hand and everything just went, and luckily it was my right side that went so I was able to crawl across to get to the phone over there and phone my son. (Brian)

Brian's main goal was to outlive his wife. As her constant carer and frequent visitor, his only wish was that he would live longer than her, that he could see her out so she wouldn't wonder why he didn't visit anymore. I later learned that he had managed to achieve this. Brian was not unique in feeling the strain of being a carer had impacted his health. Others, often women, talked of having cared for partners as they became frail and died. A number of participants were coming to terms with the death of a partner. When I visited Fraser and Eric, both sat with photos of their deceased wives sitting by them, keeping them company during long quiet days. Fraser described how he chatted during the day to a photo of his late wife, who had died from heart failure. It was days after her death when he began his own journey in developing and living with heart failure.

Well actually it will be a year in two weeks time since the wife died and prior to that I mean a year ago just now I felt as fit as a fiddle. I had the wife in a wheelchair and I could lift the wheelchair out the car, put it back in the car, wheel her up down (to the shopping centre) and that and do all the shopping and suddenly just like that, in fact it was the day after the funeral I took my first heart attack.. And ever since then its just gradually got worse but I've had a check down now and there's nothing they can do about it. (Fraser)

Accounts of failing hearts and heart break seemed to become intertwined as people told me of their own experiences of stress, loss, burden and bereavement whilst we chatted about living with heart failure. Some people talked about their own experiences with mental health difficulties, including psychiatric admissions and depression. For some men these difficulties were associated with the lasting effects of having been in the Second World War. For others, such as Helen low mood played a significant role in her daily life. Her heart failure nurse specialist wondered if she had depression, and Helen herself spoke of feeling very down, particularly in times when her illness was worse. She spoke of the constant struggle of having to collect herself again after each set back in her health and mood.

I just sit down and console myself that there's people worse than myself, pick myself up, and dust myself down, and start over again. (Helen)

The intertwining of stories of loss and heart failure was a recurrent theme for many participants. The issue of how to reconcile the feelings of loss, for many varied reasons, alongside the medical story of the heart and the discourses of being a good patient, shows how there is challenge in making sense across the many ways in which to conceptualise heart failure. In some ways the idea of a broken heart seems to contradict the science of the medicalised heart. However, there is much evidence to support the idea that the physical heart and psychological wellbeing (the social and emotional heart) are closely connected. Having depression alongside coronary heart disease in general is associated with a doubling of mortality (Barth, Schumacher & Herrmann, 2004). For people living with heart failure it is estimated that as many as one in three people will have depression (Whooley, 2006). Just what the causal relationship between the physical and emotional heart is, is unclear, as the research cannot show if depression leads to heart failure or vice versa. In people's accounts, despite persistent medicalisation into the role of patients with diagnoses and prognoses, the impact of the social and emotional heart remains firmly embedded in their own sense making about what has led to heart failure. These sorts of causes are not addressed through daily weighing and salt reduction and remain unacknowledged as important parts of some people's illness journey.

The third and final time I met with Louise she continued to broaden her account of what caused her heart failure beyond the medical account of fluid and the idea of stress. As we

talked she revealed the difficulties she had faced throughout her life that she felt had contributed to her heart trouble. These difficulties included working very hard manual jobs with long hours throughout her working life.

Louise: See I've always been on the go, I mean when my husband was alive we had the allotment I was down there everyday and I was always busy doing something, you know, plus I was out working as well at half past four in the morning cleaning. I think that was a lot of my trouble I done it too long.

RP: Okay worked too hard at a hard job?

Louise: A hard job it was that's fifteen years ago, so let's forget about it.

RP: You were doing it up until fifteen years ago?

Louise: Up until I was sixty up at half past four in the morning and get the five o'clock bus.

Louise had needed to work hard because her husband had refused to give her any money for her or their children, and so she was their sole provider. She felt this had unavoidable consequences on her health.

Louise: When I think back on it you know I say you were a fool, you were a fool, and I keep saying that to myself, you were a fool, but then I needed the money at that time.

RP: Right.

Louise: Because my husband was a wee bit tight fisted.

Louise went on to further reveal that her husband was not just 'tight fisted', but abusive through most of their marriage until he became older, more frail and more dependent on her. However by that time the damage to her health had already been done and the idea of the heartbreak of being abused, stress and fluid in her body all formed the different discourses she held about what contributed to her heart failure.

Louise: No, his tongue was worse than anything but he had kindness on its own for other people because they used to say that oh what a fine laddie (A) is oh what a cheerful man and all the rest of it and I felt like saying you don't know what's going on but my neighbour that lived above me she could have told you.

RP: Right.

Louise: She would say oh there's (A) and his tantrums again the doors would go.

RP: Okay wouldn't use his hands though?

Louise: Once, never again, no and that was through drink of course.

RP: Okay, so a long hard life can leave a bit of strain on our health and our bodies?

Louise: Well I think that's what done it I think that's what it's all built up through the years, but as I say he's at peace now, he's away, I'm happy.

5.3 Summary

In this chapter I explored the emergence of symptoms as a medicalising discourse that gives form to the condition called heart failure, even in the face of no recognised definition of the illness. Symptoms transcend individuals and provide a discourse in which to depersonalize heart failure, and provide an objectifying language in which to facilitate the provision of care. This can happen in a number of ways, and the example of using particular physical presentations of heart failure illustrates the way in which left ventricles, rather than people with needs, can be rationed in or out of care provision.

Finally this chapter explored the dialogical nature of broken hearts and the heart broken, where competing discourses about the nature of and causes of heart failure were conveyed in different ways. These communications revealed the dialogical nature of making sense of illness, particularly when the symptom based discourses, and the science they rely on, are challenged by conflicting accounts of the breaking of social and emotional hearts.

6 Relationships and the Sharing of Knowledge

Following my journey of thinking about what it might mean to be a person living with heart failure, I have moved from a thematic analysis and the potential problems of such approaches leading to generalisations, and moved on to explore how ideas of performativity and discourse have relevance to being a patient with heart failure. In doing this my goal has been to consider the different ways to understand the experiences of living with heart failure. In these next sections I want to further explore how living with heart failure can also be understood as an experience that is embedded in relationships. First I will describe those relationships, and how they might change. Then I will go on to explore how knowledge is shared between people, and consider how that can offer further perspectives on how we come to understand how people experience heart failure, as situated in a context of relationships with those around them.

6.1 Changing Relationships of Care

The various settings of heart failure each led to new relationships of care developing between people. People become patients or professionals, family become carers and different types of professionals feature in different settings. These new or developing roles needed to be negotiated and renegotiated with changing needs. Even the shift in title from spouse, wife, husband, partner, daughter, son, to that of carer and patient indicates there are new expectations. There are also relationships that form between different systems of care, particularly in the interactions between settings, such as the movement into a ward from home, or back home again, or in transferring care between institutions. Relationships develop between patients and professionals, carers and professionals, and professionals with other professionals.

Negotiating the new roles and relationships involved in care was not always easy. For Carol, needing to rely on Ray was difficult, and Ray was frustrated by the new role of carer. There were visibly angry interactions between them, and as described in Chapter 3, Carol had been angry both with Ray and with the professionals providing care to her. Professionals involved in

Carol's care had also noticed this hostility between them, and there were various speculations as to what this might be about. One professional felt it was part of Carol coming to terms with dying, another felt that Ray must have done something to anger her. Where the relationship between a person and their partner might be strained, the trust and intimacy involved in performing personal care tasks could become an activity of power struggle or difficulty. During an interview with Carol and Ray together, Ray shared a description of Carol's difficulties with constipation. He seemed to feel that she was withholding her bowel movements deliberately to annoy him, although I also wondered by offering such a private detail about Carol he was contributing to the tension between them.

Ray: Aye, it does tend to get a bit stressful at times. But it's just one of those things, you've got to get on with. I mean Carol, I shouldn't really be saying this, but we're in a constipation situation at the moment and I was losing the rag with her, because I was putting her on the loo and she wasn't passing anything.

Carol: It's because I couldn't do it.

Ray: So this morning we had a bloody big result.

Carol: No, this morning the first thing when I went I couldn't do anything and you lost the rag.

Ray: No I didn't.

Carol: And you started moaning about me.

Ray: Aye, and I started moaning that you were sitting there doing nothing I should have kept my mouth shut.

Carol: And then when I done it, I never told him I just sat there and I waited until, oh you've done it, you've done something, you've done something and then just then the nurse came in wasn't it?

Ray: Aye.

RP: So you can get a bit fed up with each other from time to time?

Carol: Yes.

Ray: Yes.

The relationships a patient had at home became an important resource to professionals in relation to meeting people's needs in the home. Carers, such as Ray, performed important and essential care tasks and at times were also offered support through the provision of paid carers

or nurse visits. The absence of relationships at home seemed to signal to professionals that other support would be needed to meet the patient's needs. What I found particularly interesting was the way professionals hoped that relationships with professionals or paid carers might come to ease any difficulties associated with a lack of family or friend relationships for a patient.

Professionals wanted to find a way to offer emotional support and reassurance. When there were fragile or non-existent family relationships they were particularly motivated to find ways to counter this absence of close personal connections. One way to do this was to put in place carers that would go into the home, or to keep ongoing contact with the patient in the institutional setting. Linda was in the position of being retained by the day hospital, with the hope it would help with reviewing her physical recovery and give her some support and something to 'hang on to' in her recovery.

I was really quite worried about how she was going to manage getting home, because again one thing that can sometimes happen is you get somebody who can pass the tests for the OT and physio, so they can wash and dress and walk about the ward, and on paper they're fine but in reality you look at a poor frail soul, who is absolutely exhausted emotionally drained, and you just think I'm not sure you are going to manage ... Some people like that will thrive when they get home because they're back with their own food, their own environment, their own support network, but again I was a bit worried that she didn't have the support network, so I thought that if we could give her just something to hang it on, that you'll be back again next Wednesday you can report in or whatever day it was. (Linda's Geriatrician)

There are some challenges to this idea of supplementing the home system of care through provision of professionals also offering support, reassurance or even friendship. I was particularly interested in the impact that relationships had on the care Allan received. Allan was an older single man, who lived on his own. He was very likeable, easy to get along with and had developed very good relationships with the day hospital staff and his geriatrician (the same geriatrician that provided care for Linda). Allan seemed surrounded by people, with daily contact with various helpers and carers. Professionals perceived this as providing the important emotional support that he wouldn't get otherwise as he had no family. However

Allan was aware of how they were all employed and focused on tasks, and didn't provide much in the way of company or support.

RP: Right, and it is good to have the help as well as the company?

Allan: You don't get much company because they're too busy.

The relationship Allan had developed with his geriatrician and the day hospital meant they decided to make an exception for him that played an important part in his wellbeing. They kept him attending the day hospital on a long term basis, as they felt they were providing an important social relationship for him. They justified this on the basis that he experiences scrotal oedema, which was frequently missed by the GP. However because of their good relationship with Allan and their knowledge of the need to monitor this symptom, it was seen as important to keep him in the service, with those good, trusting relationships, in which they could review his fluid retention.

We felt that when we've discharged him previously, he'd went to his GP complaining of an increase in weight and oedema and his GP looked at his legs and told him he was fine. Allan is a person who I have known for the last two years and he never gets or very, very rarely would get ankle oedema or leg oedema, he usually gets scrotal oedema. So even when he was admitted a few weeks back he had put all this weight on we checked his legs and they were still lovely and slim, which we wouldn't really expect of people with a condition of cardiac failure, but he did have scrotal oedema so we always have to check these areas so we feel that you know he has built up a relationship with us, and is quite happy for us to go and check. (Allan's Day Hospital Nurse)

There were other people in the study who had the same day hospital staff and geriatrician, and who were just as socially isolated. The day hospital rules were that it was strictly short term access only, and an exception was only made for Allan. I am not sure why the exception was made for Allan and not others, it may have been related to how socially pleasant he was and how close the staff felt to him. Certainly it illustrated to me how the staff could recognise the importance of social contact and how they would do all they felt they could do to ensure

people might have their social needs addressed. Mostly they were not able to address the needs directly, but would try to address that need through the introduction of paid carers.

The introduction of new people into the home setting could lead to other challenges. Helen had some difficulties with carers and had discovered one had been taking money from her. Helen's heart failure nurse had different concerns, in that she was worried that Helen relied on carers to do things that she could, and should, be doing in order to keep maintaining her independence.

I think with Helen there's a dependence on that for the social aspect, because she lost one of her carers for a while and she became more independent, and I noticed the change when she lost the carer, but she actually could do more for herself than she does, and I find that quite interesting. (Helen's Heart Failure Nurse)

One of the obvious gaps in how to support the home system of care was that there is less professional input available on the weekends. Patients and professionals described how the weekends, or other times of public holidays, such as the Christmas and New Year period, can be particularly lonely. Helen described long and lonely weekends, but these times could also be challenging as patients might need to rely on care systems they didn't have relationships with, like the afterhours phone help line NHS24. Without the known relationship between the professional and patient there emerged room for problems in managing aspects of care (particularly in relation to altering medication).

Professionals recognised the tangible benefits to forming good relationships with patients, but found some relationships easier to form and manage than others. Frank was a good example of a patient that offered a range of challenges. Frank was described as hard work and high maintenance by professionals, and despite the fact I can describe our discussions as enjoyable, I could relate to the difficulties they expressed about him. He was very forgetful, preoccupied with certain topics and it was difficult to keep our interviews 'on track'. I learnt eventually that he had been given explicit instructions by his wife Flora, to behave well in the interviews we did together. By this she meant he should answer what was asked and not go off topic. In one interview we had a good discussion about what he felt was wrong with his heart and health, although he was not aware of his diagnosis of heart failure. Eventually he looked at me very

seriously and asked if I could turn the tape recorder off because there was something he wanted to tell me. With a great sense of anticipation at what might be about to follow, I turned the recorder off and reassured Frank that his anonymity would be protected. He proceeded to tell me at length about his war time experiences, which was the topic he had been banned from discussing by Flora and did not want to be caught on tape digressing to this topic.

For professionals, however, Frank's preoccupations could be really challenging and he represented what one professional described as, a high maintenance patient. Discussions were often difficult and very circular, frustrating the sense of making shared understanding together. Frank's consultant, a woman, would draw on a gendered stereotype to describe patients as either 'high maintenance' or 'low maintenance'. In some way, this highlights the way patient behaviours also are formed into stereotypes.

Women are either high maintenance or low maintenance, patients are also high maintenance or low maintenance, and oh boy he's high maintenance, and after you've been talking to him for fifteen minutes your main preoccupation is how can I get out of this conversation. (Frank's Consultant)

Despite these challenges, the professionals involved in Frank's care were very committed to offering him supportive relationship-based care through his attendance at a day hospital. They described how they were patient, provided information in many formats to help overcome his memory problems and gave him as much attention as they were able. This involved monitoring his condition, providing him with company and was seen as directly supporting the home system of care by offering Flora a break.

Building that sense of relationship could lead professionals to describe how those relationships might substitute for a lack of family or support for some patients, but this sense of substitution was limited. Frank had become very attached to the nurse most involved in his care and when it was time for Frank to be discharged from the service he was quite upset, promising to return to haunt them like Hamlet's ghost. In some ways the sense of friendship and relationship is used to facilitate better care, but is entirely limited by the way these relationship interactions happen between patients and professionals, not between friends. Frank had asked the nurse

for her mobile phone number, at which point she clarified this difference to Frank, in that she couldn't be his professional if she was his friend.

When he was leaving he wanted my mobile telephone number, so he could phone me, but I said to him no, that wasn't really acceptable because if I give him my mobile phone we would be friends and then when he came back if we were friends I couldn't be his nurse, so he said oh right that's fine I want you to be my nurse so that's okay, I'll just phone you at work if I need you. (Frank's Day Hospital Nurse)

This highlights how the sense of friendship which might develop is complicated by the people involved and the positions they occupy. The sense of friendship offered by the nurse makes for good care, but the limits in that relationship are also defined by the nurse. The same nurse described how she had a good relationship, with a sense of friendship, for the consultant for whom she works. However the extent of that relationship is subsequently defined by the consultant. Here the nurse reflects on how all the relationships might connect, in that she was on guard against letting her care relationship with Frank result in him manipulating the friendship she has with her consultant.

She'd (the consultant) say you're the boss it's up to you, but then I have got to be careful that I don't let him manipulate me and abuse the sort of friendship. (Frank's Day Hospital Nurse)

Whilst the relationships formed sometimes led to challenges they also led to a great deal of connection and care for those patients that professionals work with. The nurse caring for Allan reflected on how you can become attached through these relationships and how she felt a greater sense of loss when Allan died, than she might typically feel. The ambiguities, benefits and challenges of relationships in care were apparent in many of the accounts of professionals and patients. One professional put it very well when she reflected on the need to feel someone cares and is interested in you, and this is something they can offer as professionals, even though you can never be the family member you are substituting for.

It's difficult to know because I'm not sure that the kind of support that she needed is available on tap, you know if I was a fairy god mother I would prescribe her a living family, I would prescribe her her sister back. I'm not sure how well we as professionals can ever substitute for family members, but I think probably she did need regular input from somebody, just even so that just so that she knew somebody cared about her, so that she knew somebody was interested. (Linda's Consultant)

The relational nature of care was also apparent in the way in which the different professionals and systems interacted with each other. Professionals came in and out of a patient's care at different times. A hospital admission could lead you to a new system of care with a new discipline, such as cardiology. Discharge back into the community would lead to you the care of your primary care professionals. Specialist heart failure nurses, occupational therapists, district nurses, NHS24 services, after hours care are just some of the different professionals that might input into the care of an individual. These different professional disciplines may have different views and perspectives, and lead to a range of relationships that have to be managed between professionals and between services. Such a variety of inputs was seen to complicate care to the detriment of the patient at times.

You see that quite a lot with patients who've got a few, just sometimes it's like too many cooks can spoil the broth, and that can happen sometimes with our patients if there's too many people. (May's Heart Failure Nurse)

Between professional roles there were tensions to negotiate, particularly between different hierarchical positions. Nurses talked most about how this played out in their roles, with the need to negotiate relationships with new registrars in the hospitals, or dealing with GP's as a heart failure nurse specialist based in secondary care. Allan's nurse knew very well what he could and could not tolerate in terms of intervention, and described how to challenge the new registrar whilst allowing the registrar, who was in a more senior position, to save face. In this situation the nurse had a very good relationship with the consultant and knew she would be supported in challenging the proposed intervention.

Allan was unable to tolerate the catheters and when the registrar wanted to put Allan on and I said no he can't tolerate them, you know, it is written in his notes that he's not to have it, and Allan being the patient he was as well said no no no this is it you know, and I said look I'm really sorry but I can't let you prescribe this for this patient, and I will have to, I know you're far more senior to me and I know you're far more experienced, but I know him as his nurse for the last few years and all his medical issues and I know that (his consultant), and I would have to go and speak to her about this, so alright, so he went and looked through the notes and he found it, but then he made his own, he justified his decision by altering something else I can't remember what it was at the moment, it's probably written in his notes, but he justified it by, you know, he didn't want to take it from me or from (the consultant), but he said oh yes you're quite right he can't have that because of this reason. (Allan's Day Hospital Nurse)

It seemed to me that these tensions between roles and sectors (particularly between acute and primary care) could play out at the cost of providing the best care for patients. Brian had heart failure and had one very clear goal, as described in Chapter 5, Section 3, which was to live longer than his wife who lived in a residential home and had advanced dementia. He visited her frequently and felt strongly that he was one of the few constant people that she could remember, even if at the time we met, she only remembered him infrequently. Brian had a heart failure nurse involved in his care, and she, in conjunction with the cardiologist had advised Brian's GP to alter his medication. This medication change was aimed to maximise the effectiveness of certain medications with the view that this was most likely to enhance Brian's longevity. When the heart failure nurse suggested this to the GP, he responded with 'nice try wee lassie'. She wondered how it would have been received if the cardiologist, had made the recommendation, and she planned to get him to make that recommendation to see if the GP can be persuaded from a different place of relative authority. For Allan's nurse, the consultant she works with made clear to new doctors from the start that she valued the nurse's view and experience, thereby used her hierarchical position of consultant to encourage new doctors to use their own new found status more respectfully.

Absolutely yes (the consultant) just so wonderful to work with you know, and that's what she always says to the young doctors when they come, and she'll say we've got to believe her because she does know and she does run the show in a lot of ways you

know, and it's really good that she holds me in such high esteem and she really feels you know that she trusts my judgment, my decisions and she backs you up every step of the way. (Allan's Day Hospital Nurse)

The relationship between disciplines also caused tension, with the example of the different approaches of cardiologists from geriatricians. Cardiologists were cast as 'personality type A boys' who discriminated services on the basis of age and were more interested in new and exciting interventions than finding ways to support people who might be approaching the end of life with cardiac problems.

Again, if you're a cardiologist and you have enough study leave to go on one course, you can either go on one course to go and learn how to work the latest toy, some fantastic drill for boring out people's coronary arteries and making pretty pictures on an x-ray screen and something really high tech, or you can go on a kind fluffy communication end of life wiffly waffly big girly sort of you know which are they going to go on? (Frank's Consultant)

The relationships between systems can reflect issues of who feels they 'own' the patient, which was also discussed in some detail in Chapter 4. In some ways the professional who is delivering immediate care may feel they own the patient, and this might be formally recognised, such as with a joint handover to palliative care colleagues. Where another system, like an acute admission, enters into providing care where there may be an existing strategy of clinical management in place it can be seen to be over riding the person who 'owns' the patient. This may also be an issue in the interface between secondary and primary care. This ownership might be apparent to patients, and Allan felt that an admission ward had stepped on his regular consultant's toes with the decisions made about his care in a different institutions. His consultant reflected on this issue of ownership as being a function of how medical systems are structured and the prevailing culture of care.

Now that may change a bit as medical structures change, as ours change, because increasingly we will have to share patients, at the moment we're still in a culture where patients are mine, they're mine and mine alone and I have a team of juniors who help me but they're my responsibility round the clock, apart from when people are on call

and all the decisions and communications done with them are by me. (Frank's Consultant)

The difficulties in relationships between systems of care, or institutions were exacerbated by the way information might not be easily shared between different places. In terms of how relationships build good care, based on trust and knowledge this is not able to be transferred and so contact with a new professional could lead to different clinical decisions being made. In terms of the potentially transferable information there was a lack of clear, accessible and transferable records on patients between institutions. An example of this was the conflict of a holistic and palliative care approach being taken with a patient in one institution, but upon an emergency visit to the admissions ward to a hospital a new care philosophy could be activated as the information about what had been agreed would not be available quickly enough.

Yes and have a holistic view, and again who have seen people over the years but yes, so mostly there is a conflict there again with somebody just the other day who we'd made lots of decisions that we didn't want to do this that and the other, ended up in the Royal Infirmary and somebody in the acute admissions unit thinks oh we should do this and suddenly kind of changes your whole focus better record keeping, better consistency of records, better kind of goals in the records so that it becomes clear if one of my patient's is re-admitted to the Royal Infirmary you can read from the front page, you can read some or very clearly that this person has got end stage heart failure, and our current goal is not to extend life expectancy, our current goal is to achieve comfort, these are the things we've done, these are things but the problem is that these notes aren't necessarily available when somebody comes in, so they get mistreated for the first day or two until they then realise what's what, so simple things like better record availability would make a big difference yes. (Frank's Consultant)

Some professionals saw their role as less about ownership, and more about coordinating the relationships between services and connecting the patient to the right services, which they might otherwise not find out about.

I would say that there's a lot of services out there ... but you need somebody who knows where they are, what to do, how to pin it all together and you know that's very much

what we do when we're looking at the patient realistically you know we can we'll join the OT, the physio, the social work, the GP, the Consultant and then you've got the volunteer service... (Helen's Heart Failure Nurse)

Whilst the movement in and out of different institutions was at times disjointed, some professionals were working at making the transitions between services more like movement to a different member of a team of services and professionals. This seemed to particularly be the case where palliative care was engaged in a patient's care as heart failure professionals wanted to be able to ensure the best care and to be able to follow through on what happened to their patient.

I also felt quite strongly that we should go together that I should go with the palliative care nurse. I think it has to be seen by the patient that this is a team you know someone you're passing the care over to. (Brian's Heart Failure Nurse)

6.2 Sharing Knowledge

My interest in describing the relationships around people with heart failure is to explore further ways to obtain different perspectives on what it means to live with heart failure in the context of people's lives. Also I felt that performances and discourses were embedded in the context of relationships, making an understanding of relationships important. One particular aspect of relationships, which I felt was very important in this research, was the way in which knowledge was shared in different ways between people. In particular I was interested in knowledge about heart failure itself, about the diagnosis and prognosis. I had come to working in heart failure from the field of dementia, where people are often not told their diagnosis for many reasons, often for fear of upsetting them (Pratt & Wilkinson, 2003). In that work I had interviewed one man with dementia, who had not been told his diagnosis, but who told me at length that one of his regrets in life was that he had not been honest with his wife when she was dying from cancer 20 years earlier, about her diagnosis (Pratt & Wilkinson, 2001). He hadn't wanted to upset her, just like those who withheld his diagnosis from him, did not want to upset him. He had come to understand as time had passed, it was far less acceptable to withhold a diagnosis of cancer than it had been at that time, and he had great regret about his decision. The way in which knowledge about illness is shared, or not shared, can offer insights

into relationships, power, meaning and the broader social discourses that are practiced in relation to disease and may change over time.

Disclosing a diagnosis of bad news might be expected to upset people, and whilst the advancements in the field of cancer, and to a lesser extent dementia may be linked to treatments, disclosing a diagnosis would likely be expected to be experienced negatively. Additionally, I had found in my previous research that withholding information when people wanted to know it was just as likely to cause distress (Pratt & Wilkinson, 2003). Telling people information they didn't want to know, did not remove the possibility of people choosing to not believe the information, as professionals often feared. I had formed the view in my dementia work, that knowledge was often withheld in a way that left people with dementia without choices. Information seemed like a very powerful expression of the way in which differences in power were manifest in relationships between patients, carers and professionals (in all combinations).

Sharing information about heart failure is generally poor, with patients often being unsure about their diagnosis or prognosis (Rodriguez et al., 2008). Despite the seriousness of heart failure it remains a mostly unknown condition (Rogers et al., 2000), just as cancer once was many years ago, and dementia was more recently. The ethical conditions of this study meant that, as for previous work in the field of dementia, I was not to mention the diagnosis in question unless mentioned first by the person with the diagnosis. Despite my fairly strong view that people have a right to know their diagnosis and prognosis, I only mentioned euphemisms, such as 'heart trouble' and 'difficulties with your heart', or in cases of uncertainty of knowing whether people were even aware that they had a heart condition at all I would only enquire after their general 'health'.

I was quite surprised at how few participants knew that they had a condition called heart failure, and how limited my ability to estimate that number would be. I could say with some confidence that those who had Heart Failure Nurse Specialists were very likely to know they had heart failure, partly because of the name of the nurses, prominently displayed on name badges and patient information. As I describe in the Methods Chapter (2.2), 9 of the 10 patients that had heart failure nurse specialists, knew their diagnosis. Otherwise I was limited in knowing with certainty, who knew their diagnosis, and only 2 of the remaining 10 (who did

not have a heart failure nurse specialist), appeared to know their diagnosis. Most knew they had heart troubles of one sort or another but mostly, only those who had a heart failure nurse specialist were aware of their condition. Of course the difficulty with not being able to mention the diagnosis is that this was only my approximation, which I sometimes got wrong, as I have illustrated with my contact with Alan (Chapter 2, Section 2.4).

In my conversations with Carol, we only talked about her heart troubles or difficulties. She felt she didn't know enough information about what was wrong with her heart and was angry about this. It was a frequently occurring situation in this research that I would be talking with someone about how they wanted to know more information, when I knew that information about them. Carol directed much of this anger about not really knowing what was happening towards her husband, who she felt was doing little to find out more about her illness despite her request that she was told more.

RP: So what do you think happened this time with you being unconscious?

Carol: This time they say I was unconscious.

RP: Right and do you think that's something to do with the heart, you're not sure?

Carol: You never get much information off them.

RP: Right do you want more information off them?

Carol: Well I keep telling him to go and see them and he keeps saying oh they'll tell you if they want you to know they'll tell you. Have you ever felt like taking and punching somebody in face?

Ray did know more about Carol's diagnosis and prognosis than he had shared with her. Carol's consultant described how there had been an incident where Carol nearly died and they had prepared Ray for her imminent death, but Carol didn't die. This was a common story for many professionals as they described their great reluctance to prepare people for dying because some people exceed their expectations. The consultant talked about how she was much more frank with Ray, but felt that it would be brutal to tell Carol she was dying when it was hard for them to know more accurately if that was likely to be the case.

We have been very frank with her husband, with her I think we've tended to use words more like you are seriously ill with your heart, and also I think to use not so much to

concentrate on prognosis, but to concentrate on saying what we can and can't do, so that you're not fostering unrealistic expectations, so I don't, I think it would be brutal to her in terms of saying you're going to die in the next year or two or in slightly better words, but what I would tend to say to her is, I don't think there is anything more I can do for your heart so what we're going to do is concentrate on making your leg a bit more comfortable or what we're going to concentrate on is getting you able to move from chair to bed so that we can get you home. (Carol's Consultant)

Tayler and Ogden (2005) asked GP's to rate what terms they were most likely to use to explain the problem of heart failure. The term most likely used was 'you have fluid on your lungs as your heart is not pumping hard enough', followed by 'your heart is a bit weaker than it used to be' and 'your heart is not pumping properly'. The term 'heart failure' was rated 7th out of 10 options. Not surprisingly, patients (and a sample much younger than the age people often are with heart failure) felt the term 'heart failure' sounded more serious and would have a more significant negative emotional impact than the euphemism 'you have fluid on your lungs as your heart is not pumping hard enough'. The researchers' conclusion was that it is reasonable for practitioners to use euphemisms, as it will avoid causing upset (Tayler & Ogden, 2005).

Study warns of dangers of telling patients too much

27 May 05

Openness is not always the best policy when talking to patients about their illness, a new study concludes.

Researchers found that giving patients stark medical terms can increase their anxiety without improving their understanding.

The study reopens the debate on how much information it is appropriate to give patients, with one GP trainer calling the findings 'paternalistic'.

Researchers surveyed 447 patients and found those told they had 'heart failure' had a significantly stronger emotional reaction than those given GPs' favourite euphemism 'fluid on your lungs as your heart is not pumping hard enough'.

They also believed their condition would be more serious, more variable over time and would last for longer, without showing any greater understanding of their illness.

Study leader Professor Jane Ogden, professor of health psychology at the University of Surrey, said: 'This study suggests the area of heart failure may be one where GPs may choose to compromise openness for sake of the patient and that this fear of upsetting people is well founded.'

Figure 6: Pulse magazine: 'The dangers of telling patients too much'

The diagnosis of 'heart failure' itself was also described by people with heart failure, and professionals, to feel like at times an inaccurate description of their state of health. Patients and professionals talked about how the words 'heart failure' conjured images of a heart that had stopped beating, with mostly patients also reflecting on how that was fairly immediately proven not to be true by the fact they were still alive, as also discussed in Chapter 4. Yet it could be fairly shocking to hear such a description of their heart.

This combination of unpredictability and inconsistency (the beating yet still failed heart) appears a central justification for the limiting of sharing information about diagnosis and prognosis. Heart failure is not well known or understood generally. In this sense it lacks cultural reference points like cancer or dementia, both of which interestingly had low diagnosis disclosure rates until both conditions were better known of (particularly in the case of cancer which also had improvements in available treatments). With heart failure, people might be given information and not have a wider context of knowledge to draw upon. One professional talked about her reluctance to share too much information because of the potential for confusion about what the diagnosis might mean.

In fact I had quite an interesting lady, just diverting a wee bit but, I went to see her quite recently and the first thing she said to me was well I know I've only got five months to live and it was the first thing she said when I got to the door. Subsequently I went back to speak to her cardiologist to make some enquiries and he had actually been annoyed because one of his Registrars had, she has got quite severe heart failure, and the Registrar had actually told her you know you've got a fifty fifty change of lasting five months. So he had been very blunt and you know, we can't ever say that. I think I would probably agree with him that I think we can say there's no cure, that's what I do, but I wouldn't quote something specific. (Brian's Heart Failure Nurse talking about a different patient)

Professionals in this research were constantly trying to work out how much information to share with patients and carers. There was a fear that giving information on the diagnosis or prognosis would cause distress, make for gloomy news, make people feel worse, cause strain

on their weak heart, upset people unnecessarily, or 'open a can of worms'. This led to a situation where heart failure was often not talked about until the very advanced stages, if at all.

Telling her she's on a knife edge probably isn't that helpful, because she's actually got quite a good quality of life at the moment (Frank's consultant, talking about a different patient)

There was also the prevailing view from professionals, that patients and carers don't always want to know bad news and that the right of not knowing should be protected by taking the lead from patients about how serious their condition might be.

I think sometimes I find I don't know with Ian and (his wife) I sometimes get the impression that there is a bit of a wall there, and I do very much take a lot of the lead from them, because I don't know that they're ready to be at that stage of approaching their prognosis to be honest with you. I think when they arrive at that, you know, in some way themselves, I think that's when you would want to, but I think the way I've seen Ian psychologically and the impact it's had on him, I don't think one of them would want to know the answer to it at the moment because I think that might actually make him feel a lot worse. (Ian's Heart Failure Nurse)

This view opens up a dance of knowledge between the professionals, who have knowledge, and the people who the information relates to. Mostly, professionals looked to see certain signs from patients as to how much information they wanted to know. This approach has certain limitations, as the professional holds the knowledge about the patient, and the patient needs to send the right signs and signals in order to open up communication about their illness with the professional.

To start with I usually ask them what do they know and I think as well as you're explaining you do get a bit of feedback you know, either verbally or non verbally, and I think that guides you as to how much you can continue. There are some patients that are very receptive to new information and you can tell that just by the fact that they are asking you questions. I would generally go through quite a lot of information on the

first visit with them, but there are others that I feel are not able to take that information on board during the first visit you know. (Brian's Heart Failure Nurse)

Sometimes professionals initiated conversations with carers and family members as a way to gauge how ready a person with heart failure felt about learning about their diagnosis and prognosis, which raised ethical dilemmas for professionals. In the case of Carol and Ray it wasn't clear if he had best represented her wishes for information. One professional talked about the right of carers to know the diagnosis and prognosis, as they are providing the care and support, whilst also acknowledging that as a professional she may also be deferring to a more comfortable option of talking to the carer given the difficulties in talking with people with heart failure.

I find sometimes I'll maybe initiate it with the carer before I'll initiate it with the patient, so I do find there are some instances I'll initiate it with the carer because I think as a whole if the patient doesn't want to know, but the carer maybe should know and have some preparation for that, so sometimes I think to myself well, should the patient know before the carer but then that's their carer, you know it's the husband or their wife or their son or their daughter and you know if they're caring for that patient that person they've got a right to know as well, or maybe it's just me I find it easier to you know to speak to the carer about it than I have with the patient (Helen's Heart Failure Nurse)

This dance of knowledge could lead to a series of good, or confusing, information exchanges. Brian knew he had heart failure, what it was called and that it was likely to be life limiting for him. Brian had a heart failure specialist nurse and because of that I had a clear reference point through which I could bring up conversations about the forbidden words 'heart failure', by asking him about his nurse, what sort of nurse she was and what sort of information she had given him. Brian was described as stable and that his heart failure was well managed. When I interviewed Brian's son, Steve, I found that he knew very little information about his father (I discuss the ethical challenges of this situation in Chapter 2, Section 2.6.2). Steve was very anxious and worried about his dad, he assumed he was so unwell he might die at any minute. However he didn't want to find out more information because he couldn't bear to know for certain that Brian was at death's door. Brian was not at death's door and the lack of sharing

information had led to much unnecessary distress – although I was the only person (having interviewed Brian, his nurse and Steve) that would probably ever know this.

The disclosure practices of most professionals appeared to be fairly similar and I asked professionals to share how they came to learn about what information to give to patients. Some commented on the role of education as being important in terms of teaching often inexperienced professionals about disclosing bad news. However, for most professionals, their practice was influenced by breaking bad news of imminent death, and that proving not to be the case, dealing with the confusion created through poor disclosure practices and their own uncertainty.

I think my attitude to that has changed quite a lot, from thinking, oh I need to tell these people, nobody tells them this is my job, to thinking, well these people don't necessarily want to know that, and you have to listen and think you know if there's something in the conversation. And sometimes you know, sometimes you drop some things into the conversation, you know about, look saying things like, you know, I'm quite honest about saying to them you're on your maximum medication there isn't much more we can offer you treatment wise and what we need to do is keep you as stable as we can. You know so I'm quite honest in that way that you know I mean some of them you know they maybe have had their questions and that and they'll say, well am I not going to get any better. And then I will say to them, no you might not get any better than that because you know it is a chronic disease you know and it can get worse, and I'll talk to them about the dips and you know the lows and the highs that you can get with heart failure, you know, so I'm quite honest about the long term prognoses if they ask about it. Or as I say, if I see that look they're coming to the end of their treatment options you know I'm quite happy to discuss that with them but unless they're actually coming out and saying well am I going to die or am I dying and if they ask me I'll say to them that you know, well yes you are, maybe. (Helen's Heart Failure Nurse)

The transfer of knowledge about diagnosis and prognosis was, of course, not neutral. The holder of the knowledge, who was mostly the professional, had the power to make decisions about what would be shared and what actions might be taken. In relation to Carol, her consultant was still trying to judge how much information Carol wanted to know. She was

trying to assess, as with all patients, how much she wanted to know based on the signals Carol might unknowingly give.

What governs when do I tell her? Again I think sometimes you need to judge what the person seems to want to know, we always give people chances to ask any questions and things and it is a difficult one to judge, how much does the person want to know things and how much do they just put themselves in your hands and let you make the decisions for them. It's difficult, for something like heart failure I wouldn't necessarily push it on them too much unless I thought they wanted more information, which is interesting of course. (Carol's Consultant)

Knowledge could be seen as a symbolic resource that reflects the differences in power between patients and professionals. That resource is sometimes shared, and sometimes not shared. There were some good reasons for not sharing information, and professionals were shaped by their experiences of telling people they might die when they didn't. However instead of altering the information sharing process, such as using this as a rationale to talk about heart failure at an earlier stage and more generally, this led to a situation of only sharing information you can guarantee to be true. The relationship between disclosure and certainty is also relevant in the area of dementia, as dementia cannot be diagnosed with 100% certainty without an intrusive biopsy of the brain. For some professionals instead of saying that a person had probable dementia to be inclusive of uncertainty, they would not share the diagnosis at all (Pratt & Wilkinson, 2001). In relation to heart failure the equivalent was to wait until death was imminent before it might seem reasonable to talk about the prospect of dying. This reflects the ideas in Chapter 4, about the difficulties for professionals to speak words that are not authoritative utterances. The outcome in both situations is that hard conversations are deferred until they are irrelevant, and the opportunity to talk earlier in the illness has passed.

The idea of telling patients the difficult prognosis of dying, is one that has evolved over time. Armstrong (1987) describes the transition of withholding a prognosis of dying as being seen as a productive secret to preserve hope, into being seen as telling a lie. As the knowledge about dying became the terrain of medicine, as opposed to informal networks of friends, neighbours or family, it was now the medical world's responsibility to tell patients they were dying (Armstrong, 1987). Some researchers have argued that truth about the prognosis of heart

failure can be told, and hope preserved at the same time, particularly if the idea of unpredictability itself, is offered as a way to maintain hope (Ågård et al, 2004). However, It is recognised there is a need for greater support of training or skill development, for professionals in sharing the news that a patient is dying in more supportive ways (Department of Health, 2008).

The dynamics of exchanging information were also reflected in carer and family relationships. Ray was doing what he felt was best in not telling Carol more about her condition, the consultant did likewise. Despite a part of me wanting to be able to identify what is 'right' and what would have been right for Carol, it is hard to say what was in her best interests, although I had a feeling that Carol should have had more say in defining what was in her best interests or not. This power of information exchange continued through Carol's family. Carol was at home when she started to have the series of painful and distressing heart attacks that lead to her death. Ray was with her at home, and in the ambulance as she went to hospital. He made sure to share limited information with their children about how she died. He told their children that she died peacefully, and even though this was not true, it was the information he wanted to share with them and the picture he wanted them to have. For me, this seemed to further challenge my position of people having a right to know information and shows how hard the truth might be to tell, if it is always required at all. Despite having argued for the right to know and open disclosure in general, I found I agreed with Ray's actions of withholding information after all.

-----Original Message-----

From: (Ray)

Sent: 2004 22:18

To: Rebekah.Pratt@ed.ac.uk

Subject: Re: Recent Phone call.

To Rebekah,

Carol passed away on Tuesday at 19.55hrs and I kept my promise and was with her to the end. Give me a couple of weeks to get all things sorted and we will have the long chat as promised. I am going to get away from here for at least a month, walkabout type thing, to clear the air and

decide where I go from here. All my family are by my side and are supporting me. Their mum would be proud of them. Regards Ray.

In relation to my research, I still have a sense that diagnosis disclosure and discussion about prognosis was important, but also a greater appreciation of the complexities of doing so. In this chapter I have explored relationships and how knowledge moves in very complicated ways between people. Often professionals occupy the position of having the information that could be shared, and they face complex decisions about what to share and how. I will go on in the next section, to explore how this issue of knowledge with all its preoccupation with truth and protection, comes to impact how people with heart failure can engage in dealing with specific aspects life with heart failure.

6.3 The Role of Symptom Discourses in Relationships

As people come to see themselves, and be seen as, a collection of symptoms, this facilitates a discourse that can be used to promote certain approaches to living with heart failure, particularly in relation to self-management. In Chapter 5, section 5.2, I discussed the emergence of symptoms based discourses as having an influential role in relation to heart failure. In this section, I will build on those ideas, but focus on relationships. The symptom and causes based discourses that develop in relation to heart failure are active in the development of the roles of becoming a patient or professional, and the relationship between patients and professionals.

But I think it's about a partnership with patients you know, the nurse going on giving them information, it's got to be the realisation that this is a chronic condition and that their help is needed in managing it. (Ian's Heart Failure Nurse)

Part of self-management being successful is the concept of compliance, which Leventhal et al. (2005) define as '*the patient's informed free choice of behaviours selected from those recommended by the healthcare provider*'. The contradictions in the idea of free choice from a limited list of options, highlights how the term 'self-management' is heavily embroiled in

professionally directed behaviour, and may accurately be used to describe patient-professional partnerships (Leventhal et al., 2005).

I first met May at her home, which was a sheltered housing complex. She had lived in this small one bed flat for some time and wasn't particularly happy there, having fairly recently been mugged at her door (despite being a secure building). May lived with constant and terrible angina pain, and was by all accounts a complex collection of terrible symptoms.

Well basically she's really becoming end stage heart failure, she's got very huge oedematous legs, she's not particularly symptomatic with her breathing. It's her angina, she's got retractable angina she's had blocks and now gets morphine for the pain. Her angina is more troublesome to her than her heart failure from a symptom point of view. Her main problem with the heart failure is the legs swell up, but even when we have got her at say a dry state with not that much fluid she has massive legs anyway. (May's Heart Failure Nurse)

The specialist heart failure nurse had been making great efforts to get May to understand her symptoms in order to facilitate self-management of her condition. She had been given clear instructions about how to monitor and report on her symptoms, with the idea that this would help May to improve her health. May resisted developing this discourse of symptoms and participating in her heart failure nurse's understanding of what self-management was, which was subsequently perceived by the nurse as low intelligence.

But mentally it's hard with her, because she doesn't retain all the information you give her, not necessarily because she's forgetful, but just you know, I've given her strict guidelines on, you know, monitoring her weight and you know how she monitors her weight and when to report it, and then she doesn't do it and then you say to her, oh well. I just thought it would get a bit better. (May's Heart Failure Nurse)

The discourse of symptoms was used or activated to promote self-management, but in the case of non-adherence, such as with May, the concerns raised are not so much about the patient managing their own condition but about failing to follow the professional instructions. This is less about self-management and more about the activation of symptom orientated texts to

help promote compliance with professionally led management of care. The use of symptom orientated discourses to deliver care provides a role also for the professional in being responsible for monitoring symptoms rather than people. By focusing on this symptom based discourse May can be constructed as the flaw in the system of care (non-compliant patient) rather than the system of care being considered problematic.

Because it's like you can give her things and then you'll say well, I gave you that before, no didn't, and then you'll say well have a little look and there it is in her file, but she's never looked at it you know, but you're giving her clear instructions on what to do.
(May's Heart Failure Nurse)

The focus on the symptom orientated discourses can limit the roles that professionals occupy. For May's heart failure nurse specialist this focus on heart failure symptom based practice led to reluctance to see May beyond her heart failure symptoms.

I think some of it well I don't think she mixes it up, because she knows her angina pain. Sometimes you can be asking her about her heart failure and she'll answer you with her angina question. (May's Heart Failure Nurse)

Self-management, even for the purposes of compliance with professional driven care is only possible if people are 'good' participants in their care. The important step in learning and understanding the symptom orientated discourses was not achieved by May in the way her heart failure nurse specialist needed, in order for them to both occupy the role of patient and professional efficiently. Immersed in the medical discourses of symptoms, May's nurse positioned her as being 'a bit thick'.

Amalgamating the research and creating a broad model of patient compliance that focuses on much more than the individual patient, indicates a more holistic model of compliance is required (Leventhal et al., 2005). However for such a broad conceptualisation of compliance to be useful for professionals there would need to be some disruption to how central the individualising discourse of symptoms is.

One way to disrupt individualising discourses is to explore alternative discourses that arise in contrast to that of symptoms. An example of this is found in exploring an alternative explanation of May's apparent non-compliance, in that she was resisting the discourse of symptoms as they did not feel relevant to her experience. When I met May she described to me how she had been living in intolerable pain for many years, and had reached a point where she was ready and waiting to die. In the absence of a symptoms discourse feeling relevant for her, it appears she resists it instead, even though this leads to her being understood as non-compliant.

May: I am very breathless, it's like a woo, I'm gasping.

RP: Right, it feels like it's taking in air?

May: Aye, it's like somebody putting you, and I think I've had everything, I've had needles injections put on my main valve through the pain clinic at the Western.

RP: Right.

May: But it didn't do any good.

RP: Oh right.

May: And then I had I think about seven things done with (Consultant).

RP: Right over the fourteen years?

May: Aye.

RP: So different operations?

May: Aye.

RP: And where's it all at at the moment? Are you saying there's no more operations?

May: No, they can't do anything. He's told the girls, he said, 'just take Mum home and one of these days she'll just sit in the chair and that'll be her'.

RP: Right, right. How was that for you, the day he said that?

May: No, I'm fed up with the pain.

Resistance to professional discourses can lead to increased pressure by professionals to comply. As illustrated by Hook (2004), power-knowledge has an aspect of authority that reinforces discourses. In relation to heart failure discourses about symptoms, one study by Sanders et al (2008), showed how cardiology-based professionals (cardiologists and heart failure nurse specialists) draw on their interventionist approach and the power of evidence based medicine to try to encourage agreement with their suggestions to patients. Cardiologists

just drew on the expertise discourse (Sanders & Harrison, 2008). Through this use of expertise, their role also becomes discursively maintained, which in turn offers the authority to reinforce the importance of discourses about symptoms with patients.

May was referred to hospice care by her GP. Hospice offered different discourses around symptoms. Heart failure was not frequently addressed in hospice and could be an area where professionals felt they did not have sufficient expertise in comparison with the more frequently admitted patients with cancer. The hospice professionals in this study described discourses of pain management and facilitating the process of dying. This in turn is reflected in different roles for people, patients and professionals, without the focus on active treatment and symptom management. For the hospice nurse, the way in which May was not able to understand information did not offer the same challenge to the model of care, rather was seen fitting with the discourses around decline and dying.

But we don't always discuss kind of deep meaningful things all the time, it can be very difficult you know, but no, May I think knows where she's going and knows where she's at most of the time you know, and we've also said you know as she gets a wee bit frailer you know, she may not fully understand everything that's happening because she might you know become a wee bit vague, maybe even a wee bit confused and she's aware that that can happen and we're usually fairly honest and open with patients about what the outcomes may be if she does become much frailer. (May's Hospice Nurse)

May eventually died in the hospice after a period of at home care, followed by an admission to the hospice ward. The discourses that hospice professionals could draw on to talk about patients were different, illustrating how context informs the development of medically based discourses. Patients were still described by symptoms, but also as whole bodies. In relation to providing hospice care to Eric, one of his needs was described as providing family support, even through providing a fresh pair of trousers and toothbrush for his daughters who were with him in his long process of dying. The hospice nurse described a conversation she had with Eric's son about the decision to have a post mortem or not. She was able to describe the stress of this decision, with his son feeling they were going to be 'cutting his father up'. Eric was in this context a whole body, a man, and a father and not so much a collection of symptoms.

However, despite this more whole person discourse there was still an expectation of clear roles for professionals and patients, as illustrated by the hospice nurse describing the difficult conversation about the post mortem. The nurse talked with Eric's angry son about this discussion and the conversation led her to cry, which she quickly questioned as not being professional behaviour.

I said right just stop there, because he's in the middle of the town from a phone box and he was distraught that they were going to actually even think about cutting his father up... You know and I can understand that, so I was a bit sad that was my only regret that it ended on that note you know. I mean that was fine she gave me the phone and I was able to say look okay that's fine and they were going to you know obviously talk too, I did come off the phone and burst into tears how professional is that. (Eric's Hospice Nurse)

The symptom orientated discourse of heart failure leads to individualising, which further contributes to distinctions being made between what constitutes the good or bad patient. This helps to define the role of what it is to be a patient from both the perspective of the patient and professional. Professionals also struggle with what defines their role and what it means to be good or bad professionals equally. In relation to the use of symptom orientated discourses some professionals reflected on how they might have responsibility for being good or poor at communicating around these discourses. Ian's heart failure nurse specialist highlighted how difficult it can be to know what the right information is and how it there are complexities in understanding what a patient is communicating to you, including the potential for the professional's own communication deficits. In terms of her own role and identity as a professional and a nurse she was concerned about how she would know if she was undertaking communication in the right way.

I think for professionals, I think we need some more information on counselling, for instance maybe a course on counselling skills or even communication skills or you know some sort of interviewing I suppose you know. Because although as a professional you're maybe doing it, you're maybe not doing it the right way. (Ian's Heart Failure Nurse)

Professionals struggle with their own role and identity and in this sense equally become medicalised into the role of medical professional. This includes confronting how to discuss death and dying, and how to deal with the impact of your patients dying. Ian's heart failure nurse identified herself as not wanting to appear inexperienced and finding a way to deal with the upset of losing patients. She took guidance from other medical professionals, both within her team and with local hospice staff to help guide her through the development of her own role as a professional.

Allan's nurse also reflected on the difficulties in how the roles of patient and professional develop. Allan was described as being a very good patient. He was able to engage with the symptom based discourses, to learn, observe and report on symptoms as expected.

I think he just feels you know he notices symptoms right away whereas other patients might not notice the symptoms don't seem to know their bodies as well, but then when you say have you, oh yes I have been short of breath, whereas Allan would just say oh I've been out of puff all this week or you know my scrotum's a bit or my tummy a bit blown up you know. (Allan's Day Hospital Nurse)

This information was used by his professionals to monitor him and control his heart failure. However Allan's nurse felt he started to hold back the reporting of information when he started to deteriorate, and his heart failure became less controllable. In this sense the symptom discourse and its tendency to encourage self management approaches began to disintegrate as Allan became more and more unwell. It does raise a question of how well symptom based discourses work when chronic illness transitions into the decline towards dying. Allan's nurse reflected on how he became a less reliable observer and reporter of symptoms as the self management 'partnership' became less successful.

Because I think probably why he didn't say things to us is because he always saw us as promoting his health and he was defying laws and we were making him better and I think he knew this time we couldn't, and I think that he felt this is it I'm dying that he's letting us down in a way as well. (Allan's Day Hospital Nurse)

Shortly after this discussion with Allan's nurse he died. She had known Allan for a number of years and knew him very well, but always within the frame of reference of the symptom based discourses. The idea of what it is to be professional was challenged by Allan's death as whilst she wanted to attend his funeral, she felt she wasn't able to, fearing she would be seen as over involved with her patients.

Nurse: I don't know if it's professional or not for the nurses to go to funerals? We felt it was the last thing we could do for our patients, and I know that had I went, I went to a few patients that I know here when I had been off duty and Allan is one that I really would have wanted to go to his funeral.

RP: You were away at that time?

Nurse: No I was here but I couldn't get off. And it was really funny because I was thinking about it and I spoke to (Nurse) and I know that (Department Manager) is excellent, but I think she thinks I get too involved with the patients. (Allan's Day Hospital Nurse)

6.4 Summary

In this chapter I have explored further how the individualising and objectifying discourses of symptoms impacts relationship and roles. The symptom based discourse also influences the development of patient and professional roles. As symptoms become a focus, patients are expected to learn, observe and report in the name of self management, which offers a clear expectation of the role of patient. Professionals draw on notions of expertise and evidence to support their role authority. Professionals and patients struggle to always know what their role is, and this becomes particularly clear when a person begins to die from heart failure and the symptom based discourses lose their relevance and discourses that resist the focus on symptoms develop. Professionals also talked about the challenges to their professional role in relation to dealing with death, and the tensions apparent in being seen to care too much by their peers also help to set the parameters for their role. I also began to consider how people might come to resist such discourses, and I will consider this further in the next chapter on unpredictable dying.

7 Unpredictable Dying

A central argument of this thesis has been to identify, explore and challenge the ways in which research on living with and dying from heart failure can lead to an individualising of those experiences. I have made the case that such individualising is closely associated to the way in which research contributes to constructing people as patients. Researchers, and professionals caring for people with heart failure, run the risk of making claims about those 'individualised objects' that can be used to make sense of people's experiences in ways that reflect a tendency to medicalise, shape or even attempt to control that experience. In this chapter I aim to explore the idea of 'unpredictable dying', drawing on the various approaches I have explored to this point, and considering how it relates to ideas such as structural violence.

The literature on structural violence predominantly focuses on the role of infectious disease as a biological expression of oppression in the developing world. I will begin this chapter by exploring how that association is made in relation to HIV in Haiti. I then will establish the case that we should consider issues of structural violence to be relevant, by exploring the relationship between the broader epidemiological context and coronary heart disease. This means I am making the case that chronic disease is the developed world equivalent to infectious disease, and is a biological expression of oppression.

I then go on to argue that in order to understand the processes through which structural violence is expressed in chronic disease, we need to consider new methods that illustrate that oppression. In the developing world, those processes are more obvious, and might include acts of violence, war or political disruption. In the developed world, biological expressions of oppression can be explored using approaches such as performance, discourses and institutional practices. Finally I focus on 'unpredictable dying' in particular, although this analysis could be applied to other aspects of living with heart failure, as it always felt to me in doing this research, that the influence of structural violence on dying was the most definitive act of violence.

7.1 Structural violence and the Biological Expressions of Oppression

In January 2010, whilst writing this thesis, an earthquake struck Haiti and what followed was one of the world's worst humanitarian crises for decades. What was revealed was how the impact of years of conflict, oppression, exploitation, pressure from agencies such as the International Monetary Fund and political meddling from superpower neighbours, had left a chaotic land, with limited security and very limited infrastructure. It was widely recognised that this amplified the impact of the earthquake, contributing to the deaths and injury of many, yet a silent earthquake of HIV and TB has ravaged Haiti for decades.

The mechanics of oppression are easily seen in accounts of third world countries, where infectious diseases follow trails of war, destruction and oppression. The recent earthquake served as a reminder of the severity of natural disasters also being connected to such conditions. Paul Farmer has documented these in his accounts of structural violence (1999, 2004). He argues that an analysis of structural violence is necessary to expose the mechanics of oppression, which have a political and historic origin but are expressed biologically (such as with the spread of infectious diseases) and reflect wider societal inequality. Farmer makes a compelling argument that in the backdrop of military force, extreme poverty and an oppressive history, the spread of HIV in Haiti is the voice of structural violence. It is not hard to be convinced by Farmer as he, as a physician and anthropologist, tends to the casualties of this biological expression of terrible oppression.

In this thesis, I became involved in working with people who were dying with heart failure, the only coronary heart disease condition that is rising in Scotland. Scotland is nowhere near the extremes of Haiti, but I wanted to explore how an analysis of structural violence, and the war without bullets would lead me to better understand why a research participant might die a terrible, never investigated death following a possible overdose given by medical professionals involved in caring for her (see the introduction for a discussion of Linda), why another participant (as I will discuss in detail in Section 7.3.2) might die essentially tethered to a non mobile oxygen machine when she could easily have accessed a mobile one should the professionals involved in her care have communicated to each other, and why another woman, living alone, and lonely for her deceased husband, in so called 'secure' sheltered housing, in extreme pain and fear (following being mugged on her doorstep (see Chapter 6, Section 6.3)

would be perceived as being '*a bit thick*', or even non compliant, when she expressed feeling ready to die. How was it that my visits to people living with and dying from heart failure took me to the worst parts of the city I was working in? Why was it possible for so many participants to die whilst on a waiting list to receive essential adaptations to their homes such as stair lifts or shower cubicles (described in Chapter 3), things that make daily life less difficult, if you have the resources to afford them?

Those experiences prompted me to explore how the ideas of Paul Farmer and Cathy McCormack were relevant to heart failure. Is heart failure a biological expression of the wider forces of oppression, or structural violence, in Scotland? Is the war without bullets finding its casualties in broken failing hearts, with poorer people in Scotland being much more likely to develop heart failure and then go on to die more quickly from it (McAlister et al., 2004)? Heart failure is debilitating, poorly understood, a low profile disease and leaves people severely restricted in their daily lives.

There are benefits from considering heart failure in terms of structural violence, or the war without bullets. Such an analysis has the potential to complement, and challenge, the largely individualising ways in which heart failure is currently understood. It makes sense to take this approach, as health and long term conditions are starting to be understood more broadly in relation to inequalities, complexity and multiple-morbidity. There is an increasing movement to a broader view of disease than a single, biological perspective of conditions. Scotland is a world away from Haiti, but in this thesis I think we can learn from Farmer's approach, alongside others, to explore non-individualising, more holistic accounts of illness and dying. However, for Farmer's ideas of structural violence to apply after the 'epidemiological transition', and relate to work such as McCormack's (2009), the idea of biological expression of oppression has to undergo a kind of epistemological transition itself.

The vast and comprehensive social epidemiological research would indicate overall that being poor, being stressed and experiencing stressors in your life, will damage your heart. For some professionals, it was clear that there was a connected relationship between physical and psychological need.

I think that she was a classic in a way for heart failure, because she had the physical and the psychological needs and the two things made each other worse. She was exhausted physically and emotionally drained and you can kind of cope with one if the others okay, but you can't cope with both and she had both. (Linda's Geriatrician)

However the same geriatrician went on to describe how, in relation to a different patient, physical health was seen in many ways as distinctly different from emotional life, and that there was a prioritising of one over another, as opposed to seeing both aspects of life as intertwined.

The community psychiatric nurses are very good at dealing with people with low mood and have a lot of community networks, but again with her it was very much a physical thing as the primary cause, but I don't know whether they would have taken her up. They weren't involved with her, but I don't know whether they would have taken her up in those circumstances. (Carol's Geriatrician).

7.2 The Processes Connecting Structural Violence and Individual Experience

In this section of this chapter I am focusing particularly on the idea of unpredictable dying in relation to heart failure. Having established that dying is heavily influenced by both socioeconomic factors and external stressors, I will now explore how different perspectives within my dialogical framework of analysis, can facilitate an exploration of the processes that might mediate structural violence in relation to living with heart failure. By doing this I aim to highlight some of the social processes that mediate structural violence in relation to heart failure.

A driving motivation for the perspectives I have explored in this thesis was the sense of disconnect I felt between the lives of the people I interviewed, and the way research (including my own), categorised, described and theorised their experiences. I considered that the disconnect was located in the way in which research methods can individualise people, and remove them from the context that offers insights into collective experience, such as how developing and dying from heart failure is influenced by socioeconomic factors, or how people

may have non-medical views about their condition. Whilst I did not focus on social inequality in my research, I felt those inequalities were important. I am not unique in finding this connection in heart failure. One US study on heart failure identified the financial barriers to receiving treatment, from having inadequate health insurance making it difficult to seek medical care or obtain the necessary medications (Horowitz et al., 2004). The study quotes one participant as saying *'Like I say, I just feel that I am stonewalled now, not by my medical condition, by my social condition...'* (Horowitz et al, 2004, page 636).

One way in which people with heart failure were viewed as separate from the broader context of their lives, was through perpetuating certain ideas about heart failure. One particularly strong concept, was the idea of 'unpredictable dying'. The idea of 'unpredictable dying' appeared in this research as being a key influence articulated by professionals on their thinking about the practice and care of people dying with heart failure. To understand the idea of 'unpredictable dying', it makes sense to first start with the way in which people with heart failure describe their experience of survivorship. Dying is the one most predictable and universal life event. Patients with heart failure talk about death and dying as part of their lives. They practice escaping death with a sort of regularity that keeps a constant reminder about the prospect of dying. For professionals, though, death seems like something they should not mention given the unpredictability of the event. Without more confidence in the likelihood of death, to avoid distress it should not be mentioned, although, as I explored in Chapters 4 and 6, this approach may also serve to protect and maintain their own sense of authority. I too was not able to mention dying and death unless the participants did so first, despite these being usually regarded as a certainty in life, out of my ethical obligation to not disclose unknown information. In the following subsections, I will illustrate how I see structural violence expressed in daily life with heart failure. I will do this by drawing on the different methods explored throughout this thesis, and hope to explore how social processes mediate, or perpetuate the experience of heart failure as a condition disproportionately experienced by those living in the most adverse socioeconomic conditions.

7.2.1 Conflicting Discourses of Dying

People spend more time not dying with heart failure, than dying with heart failure. I heard many accounts of daily life with heart failure being punctuated by serious and life threatening events that people had survived. Even when people found they had retrospectively experienced 'silent heart attacks', being diagnosed with heart failure often related to a serious situation that raised the possibility of dying. One participant, Sue, was told to go home and prepare her family for the worst, 11 years before I met with her. She had followed that advice, and although she felt had she worked hard to find acceptance about the prospect of dying, she regretted the distress it caused to her husband and two children.

And in May 1993, one of my last at that time, visits to the cardiac clinic they decided that there was nothing else they could do for me and that they were just going to leave me to the tender loving care of my GP, and that you know they said I wasn't going to live, and they said I should tell my family and all the rest of it. So I came back, went to see my doctor and (Dr) said, I said I wasn't going to do it and she said I think you should you know because you never know there might be something that your family somebody wants to say or do or something you should really tell them. So she persuaded me to tell them because I believed what they said and then here I am eleven years later. (Sue)

There were many vivid accounts of survivorship in the face of near death experiences by participants. June had one of the most remarkable accounts of her close brush with dying. She was having her heart activity monitored over a 24 hour period. She was out shopping at her local supermarket during that time and took what she described as a 'funny turn'. During this 'funny turn' she had the overwhelming urge to throw herself against a wall and at the same time pound her fist onto her chest. She didn't think too much of this until she was having her results of her heart monitoring read. The consultant informed her, with much amazement (for both of them), that this 'funny turn' was in fact her heart stopping, and her actions had restarted it. She was admitted immediately. June's actions had actually restarted her heart and she had saved her own life.

When I went in this wee doctor, he reminded me of my grandfather because my grandfather was small like that, and this doctor come in and he's such a busy body. He said I want you to get into that bed and I'm going to put all these things in. I said what's wrong with me and he said you've had a very nasty experience, a life threatening experience and I'm looking at him and I'm thinking well the man's mad ... (June)

More common accounts though were of the 'silent' heart attack. These were events that happened without you knowing, but caused damage that contributed to heart failure developing. The idea that your heart could suffer an attack without you knowing could seem unbelievable and enhanced the sense that you were living under threat of an event happening that might threaten your life without necessarily knowing it.

And through my ignorance of course I asked him what causes a large heart, what is it, and he said it just means its floppy squiggled because you've probably had a couple of heart attacks at sometime you know, and well its just hard to believe because you always get the impression you know when you have a heart attack ... apparently not you can have them without realising it. (Ian)

People with heart failure develop discourses of surviving through life threatening events, and living with a continued risk of dying. This discourse has the idea of death and dying at its core, as something that has been evaded and something that is part of the future. Death is not described as unpredictable, rather as inevitable, for some it was upsetting and for others it was seen as desirable. Many people describing living much longer than their expectations, or the expectations of the professionals they received care from.

Professionals had similar experiences of people with heart failure living much longer than expected. A patient might seem very poorly but respond very well to the limited interventions available them, or just for no apparent reason continue to live beyond medical expectations.

Well we've been saying her prognosis is terrible ever since I met her and that's now years rather than months. (Carol's Consultant):

Not being able to offer a more precise idea of how long someone might live presented a number of challenges to professionals. Professionals described how it could make it hard to know when to engage further specialist palliative care input. Hospice staff in particular talked about how this lack of precise prediction caused difficulties in knowing how long a patient might need to occupy a bed for. They expressed a reluctance to have someone occupy a bed for 'too' long, as that person could then witness more people dying around them of more predictable malignant conditions than perhaps they should.

It can be extremely depressing if you've got a patient you thought was going to die and hasn't died, several months have passed this patient could have seen six or seven people in the same room dying, is that just horrendous that's just awful for them.
(Hospice Nurse)

The inability to accurately predict how long someone might have to live also offered a challenge to the sense of professional credibility as their predictions of imminent death may turn out to be wrong. This may contribute to the very limited communication about end of life decisions between people with heart failure and professionals, which was found in this research and is also reported in the literature (Rogers et al., 2000; Selman, et al., 2007).

People living with heart failure continued to live with the prospect of dying. Whether or not people had discussed the prospect of dying with professionals, the prospect of dying was apparent in the many life events that surround them. June described how during hospital admissions fellow patients would be moved into side rooms, or die on the ward, which reinforced the sense of dying being a prospect. She came to fear the hospital as a place that represented death, but through her own strong sense of faith didn't fear her own death. Instead, she felt she had witnessed in hospital the terrible struggle some people had in dying and hoped her faith and acceptance of the prospect of dying would lead to a more peaceful death for herself.

It's a very funny, it's a strange thing that it's funny sometimes when you take these attacks and you're lying in a ward and you're listening to other people, and you say to yourself, some of them have got such a struggle to die you know ... And in that ward thirty one it was a really ill ward you know, it was a heart ward and it was an ill ward,

and sometimes they couldn't breathe you know. Then all of a sudden you'd wake up in the morning and you look across and they weren't there you know. (June)

For a number of the older men in the research the prospect of dying had been one they had faced before in their experiences in the war. Some were able to talk about this more fully than others, some even showing me the shrapnel still left in their bodies, but this group of men talked about how to cope with the prospect of dying. Perhaps heart failure, with its disobedient heart and constant state of unexpected risk felt like a related set of circumstances.

Somewhere between survivorship and death is the time at which 'nothing more can be done for you'. The experience of living with heart failure is punctuated with many surgeries, medications and procedures. People had experienced surgeries such as double or triple heart bypass, pacemakers and angioplasty (or unblocking of the arteries). Many had years of managing the pain of angina attacks, discomfort of breathlessness and extreme tiredness. There came a time for all of the participants where there were no more surgeries left to help them and that their heart failure was now a terminal condition. People were told in many different ways that there was nothing more that could be done to improve the condition of their heart. Some, like May, were told quite clearly by her consultant, but others, like Ian, were left to come to the conclusion that the doctors could do nothing further to help on their own.

I said, well I said, is there any advantage to me to stay in, he says well no not really he says there's nothing that we can do or give you that will help you know, so that sounded charming anyway you know, that was a big help. And that was as far as we are concerned we can't do anymore for you, you would be as well away home out the road so they said (laughing)... (Ian)

Other people had been given plenty of time to think about dying, particularly when they felt they were living beyond expectation and were now on borrowed time. For Allan he was two or three years beyond his doctor's prediction and had adopted an approach of trying not to think about dying all that much. Although in the following text he refers to it with the same ease as thinking about what to have for lunch, indicating an integration of the prospect of dying into daily life as opposed to something that was avoided or that he was denying.

RP: Oh right, have you been thinking a little bit more about that, have you been thinking a wee bit more about that and what's ahead?

Allan: Well my Doctor, if you speak to her if she's got time you'll find about two or three years ago she thought I was going to die.

RP: Right and here you are.

Allan: I'm still here you just never think about it.

RP: Right.

Allan: I mean the auld saying is if you've heard it is "you die if you worry you die if you don't so why worry at all".

RP: Right well that sounds like a good saying.

Allan: Aye well the thing is, I wonder what I'm going to have for lunch.

Whilst people with heart failure drew on discourses about death and dying in a number of ways there was a strong sense that professionals preferred discourses that avoided talking about dying directly, instead drawing on phrases such as *'there is nothing more we can do'*. The avoidance on the part of professionals of talking about dying seemed heavily influenced by the idea of 'unpredictable dying'. The phrase 'unpredictable dying' described how once a person is closer to death, professionals feel that unless they can be very accurate about prognosis, it should not be shared with the person with heart failure so they do not become alarmed about the prospect of dying. However dying is only unpredictable in relation to individual patient care, yet in patient discourses, it is the idea that dying is inevitable and the unpredictability is what is predictable.

These discourses of unpredictable dying from the points of view of people with heart failure and professionals are in tension with each other, although they do not exist statically, and professional discourses also vary between approaches. At points people with heart failure talk about not wanting to know about dying, and professionals describe times that they do raise the prospect of dying with their patients. Professionals wait for the cues from patients to initiate discussion about prognosis and end of life (see Chapter 6), resulting in a silence about these issues, which was also reflected in the literature (Selman, et al., 2007).

There is an impact that arises from these conflicting discourses about dying, in that it can perpetuate the lack of communication of dying and it can become unclear to professionals

what sort of aspirations people may have for how their lives might end. As patients continue to move along on this erratic journey they can continue to face further life threatening events and what should be done in the event of a threat to life can become unclear. Patients talked about their wishes not to be resuscitated, but didn't always share this with professionals. These discourses do not exist without the influence of authoritative power, and where there is ambiguity, such as when an unconscious patient is being admitted to hospital, the professional discourses dominate, particularly in the absence of an alternative view. I saw one instance of a professional indicating 'do not resuscitate' on patient notes without any sign that there had been discussions with the patient about this decision.

The discourses around dying perpetuate an idea that it can only be broached with a patient at just the right time, and that time will be determined by the medical professionals and not the patients. Allan's nurse described the 'right time' to talk about dying as being not too soon, not too late, but three quarters of the way in the journey towards dying.

Quite a distance away, not too soon I don't think, I really don't think you should do it too soon, but then I don't think it should be left too late either so probably when they're sort of three quarters of the way you'd start discussing it and if the patient was happy to discuss it. (Allan's nurse)

However Allan already knew he was dying, referring to this sighting of a hearse as passing his future. It is not that a professional had broken this news to him, but it was apparent to him through his own health and surroundings.

RP: Oh that sounds good, and have you had any thoughts about the future and what's ahead for you?

Allan: I just passed my future this morning.

RP: Did you?

Allan: Aye, a hearse and two strollers.

RP: A what?

Allan: A hearse it was going to the crematorium.

RP: Oh a hearse, do you think?

Allan: Aye. I've never said anything to them, like I said that's how I feel. We were in a patient transport at the time.

Palliative care could make an important contribution to the options for care at the end of life, for people with heart failure (Thompson, 2007). However open, careful communication about prognosis would be required in order to effectively engage palliative care in the end of life care for heart failure (Thompson, 2007).

The idea of sudden death, as in heart failure, is quite different to the way in which people might die from cancers (Chattoo & Atkin, 2009; Rogers et al., 2000). Both in my research, and in the literature (Chattoo & Atkin, 2009), heart failure does not have the same focus on pain control as cancer, and palliative care is often activated when there is a need to help support better pain control. Rogers et al (2000) describe palliative care and cardiology as having different semantic, historical and practical aspects, which influence and shape their different perspectives on dying.

The need to make decisions about such things as resuscitation, makes clear the usefulness of better communication about patient wishes around dying. This includes communication of such wishes between professionals who, without clear patient communication (or indeed a patient may be unconscious) relies on the way professionals communicate with each other, or on the availability of notes that may not always be in the same location as the patient. These failings in communication between professionals and patients, and between institutions through the lack of accessible notes, lead to deferring to professional views on best care.

7.2.2 The 'Othering' of those Dying with Heart Failure

I have argued that research and practice have made great efforts to define or create the heart failure 'subject', and this subject is also one that is constructed as unknowing and without self-awareness about either the condition of heart failure or the prospect of dying. The discourses around dying are embedded in contexts that reflect professional views that talking about dying can be harmful. My own experience, and that of other researchers (Rogers et al., 2000; Selman, et al., 2007), was that professionals often claimed patients would be upset by talk about dying, yet patients seem quite comfortable to have those conversations with

researchers, and in contrast, many see dying as inevitable. The literature indicates that patients believe that their doctors didn't want to talk about end of life, to the extent that they felt they couldn't ask their doctors for information (Rogers et al., 2000).

The discourse of unpredictable dying serves to legitimise the authority of medical professionals, who can make decisions about care at the end of life without the need to engage with their patients, indeed they may not engage with patients if they are considered to lack self awareness. These processes of discourses that perpetuate certain ideas about 'the subject' are embedded in broader social dimensions. In the example of South Africa, Butchart (1996) offers a compelling account of how medical practices relating to African migrant workers in mines from 1900 to 1950, subjected workers to what was described by Foucault as disciplinary power. Through subjecting the workers to medical examinations, tests and experiments, medical officers were able to label, categorise and test certain key attributes. This effectively took people, and objectified them into anatomical parts, such as lungs that could withstand certain levels of heat and humidity, as produced in testing chambers for a 'heat tolerance test'. The workers were also required to undertake such tests naked, and whilst being subjected to constant labour and instruction by a 'boss boy'. This degradation of the African workers reinforced apartheid. Research continued over this time to racially categorise migrant workers on the basis of anatomy, personality and behaviour, with the idea of establishing which 'types' of Africans would best cope with the working conditions of the mines, which lead to criteria for the selection of workers (Butchart, 1996). Butchart (1996) describes this as the relaying of disciplinary power, where intermediaries perform the exertion of such power because they may also be compelled to do so. As such, the medical offices and recruiting agents also become subject to that same disciplinary power as they follow the criteria and instructions for selection.

The point that Butchart (1996) so clearly makes is that the perpetuation of discourses that dominate and oppress is fluid. He illustrates how Foucault's idea of power-knowledge develops dynamically, with discourse creating and perpetuating further discourse that reflects the broader social, historical and political context, which in this case was apartheid. The disciplinary power becomes perpetuated institutionally and acts upon both those that are oppressed (the migrant workers) and those that oppress (the medical authorities themselves). I make the case that similar oppressive social processes exist in relation to heart failure. The

discourse of unpredictable dying, individualises dying to the extent where professionals feel they can no longer tell patients about their prognosis, despite the contrasting patient discourses that indicate they do have awareness of the seriousness of their condition. The withholding of knowledge from people about their condition or prognosis supports an idea of subjects without self-awareness, which again patients contest, but ultimately leads to a breakdown in communication. The consequence of these processes is that the medical authority retains the power to make decisions about dying, about access to palliative care and specific aspects of care (such as do not resuscitate orders).

7.2.3 Performative Utterances Without Authority

Whilst there are discourses that develop around the idea of dying with heart failure, the words used around dying with heart failure also reflect the ways in which broader notions of authority and language are connected. I considered the idea of performative utterances earlier and drew on Butler to look at the role of performance and how it is involved in making the good patient. Butler's work shows how we perform or resist the norms that are around us, and we have to do one or the other of those things (2000, 2005). She describes how in performing gender we can only ever attempt to be all that a gender is meant to be, but this is never totally achievable. The norms serve to help define who we are and are embedded in the social environment. These norms are discursive and not always in our control.

The effects of performatives, understood as discursive productions, do not conclude at the terminus of a statement of a given statement or utterance, the passing of legislation, the announcement of a birth. The reach of their signifiability cannot be controlled by the one who utters or writes, since such productions are not owned by the one who utters them. They continue to signify in spite of their authors, and sometimes against their authors' most precious intentions. (Butler, 1999, page 116)

Whilst few people are told of their diagnosis of heart failure, fewer still are told of how serious and life threatening their condition may be. Perhaps again, the idea of the performative utterance can be applied to such an authoritative life act. During the time of the research conducted for this thesis, the British Heart Foundation ran a national newspaper campaign to

highlight the role of their nurses in caring for people who were dying from coronary heart disease, including heart failure, see Figure 7.



As she rang the doorbell, Kate's mind was still mulling over all the day's visits.

A beaming Bob opened the door as she was still admiring the crocuses. He was dressed.

On his bad days he never made it out of his pyjamas.

*"You made it then,
I thought you'd forgotten
all about me."*

*"Well, I had nothing better to do
and I was in the area," Kate replied.*

*"You better come in then.
Don't forget to wipe your feet,
I've just hoovered."*

She smiled to herself. It was Bob's way of telling her that he was feeling better.

"So, you going to make us a cuppa then?"

***"No Kate, you put the kettle on.
I'm the one who's dying."***

It made them both laugh. She hung her coat up and noticed the gauge on his oxygen bottle had hardly moved. He was using one bottle a week when she first visited him.

"You get the biscuits then," Kate said.

As he reached for the tin she could see that, at least for now, Bob was more comfortable.

Even when there is no cure for heart disease, a BHF Nurse can make all the difference in the world. Please help **BHF NURSES** care for more people living with heart disease. To donate to the BHF Real Valentine Appeal call 0800 389 7087. Or to find out more visit bhf.org.uk



Figure 7: British Heart Foundation National Advertising Campaign

This campaign had a particular focus on the words '*I'm the one who's dying*'. This phrase is placed in a context of a caring relationship, blooming crocuses, sharing a laugh, and getting the kettle on for a nice cuppa tea. If what we say, is what we do, then perhaps this offers an interesting perspective on how this most important utterance, becomes said very rarely to people who have heart failure.

In addressing Butler I raised the question about what utterances such as 'you're dying' or 'I'm dying' might mean, particularly if the patient doesn't die. It undermines the authority in making the utterance, or perhaps, telling someone they may be dying when there is a chance they may live beyond the clinician's expectation, could erode the sense of professional authority held by that clinician.

Frank (2005) describes the pressures on professionals to develop monologisms, where a unitary, definitive account is developed.

*Young professionals are taught that in order to be recognized as a professional, and to sustain the prestige of the profession in society, they must utter words that claim to be the **last** word, the definitive, finalizing word, about those who fall within their purview, whether these are patients, students, defendants, clients, or research participants whose participation has definite limits. (Frank, 2005, page 967)*

In relation to the idea of unpredictable dying, the ability to have the last word is strongly challenged, again perhaps discouraging professionals from talking about diagnosis and prognosis for fear of undermining their own sense of authority.

There is also a lack of awareness on the part of professionals that people do often understand they are dying. In this example May's heart failure nurse interprets May's lack of surprise to be told she is dying as being an unusual reaction. The nurse considered death and dying to be knowledge held by professionals only, and as such, it should be news to be told you are terminally ill even when that might be apparent already to the person with heart failure. The nurse's interpretation defaults to a position of defending professional authority by seeing it as being something wrong with the patient in her reaction, and excludes the possibility she may have already known.

May's nurse: So whether she knew (that she was dying) all along, because like I had never said to her that she was terminally ill but you talk about heart failure and things like that you know but you often are waiting for openings if people want to talk about it you know. I had never discussed death and dying with her at all but (Dr S) obviously had this time you know.

RP: Right, right and is the impact it had hard to tell?

May's nurse: It was like she wasn't bothered.

If performativity is an act of social control (Salazar-Sutil, 2008), and discourses a production of broader social norms, the effect of those is not just upon people with heart failure, but acts upon professionals too. Professionals struggled with how they should perform the role of professional, and as this heart failure nurse points out, it can be very difficult for professionals to feel exposed as being inexperienced, to feel a sense of failure or responsibility when a patient dies, or struggling to know how to talk about dying.

Before I went on holiday I was actually feeling quite upset. I had just had so many of my really sick patients die, and of course they are the ones that take up most of your time so I spent a lot of time with them. Although, you know, I used to come back and speak to (supervisor) about it because of his sort of clinical position, because that's often the bit I struggled with. They didn't know what to do with the tablets. You still feel it's you the one out there on your own, in the house being asked like what's it going to be like when I die? And you don't want to be seen as, I shouldn't say inexperienced, I'm never afraid to say, well actually I'm not sure, you know, but when it's support they're looking for you feel like you need to be in that position to give it and often you're sort of struggling which I think is why the hospice were really valuable to me as well because I felt I was getting support as well. (Eric's Heart Failure Nurse)

7.3 Dying from Heart Failure

Most people in this study accepted that dying was one of the predictable aspects of their future, just as near death experiences had been a feature of their past also. This research was a palliative care project and there was an expectation, by the research team who designed the study, that up to half of the people recruited into the study would die during the six month period I would be in contact with them. However they didn't, and eventually I was asked to approach our recruitment contacts to see if they could refer people into the study who were more unwell, and considered more likely to die during the next six months. Despite this strong notion of 'unpredictable dying', once I had highlighted the need for people who were at risk of dying to be identified, professionals seemed able to make quite good predictions about which patients were likely to die sooner. Six people died during this study, which was fewer than had been expected. Throughout this thesis, I have built the argument that failing to put qualitative work in a dialectical relationship with information about the context of people's lives including their socioeconomic environment, runs the risk of research perpetuating a kind of structural violence by continuing to build an individualised subject, whom we can theorise about, intervene upon, and express dominant social or biomedical values upon.

There is a case for talking with people directly about inequalities, particularly in group formats, as a way to explore the relationship between inequalities and health. However I am also making the case that structural violence, which may be more easily apparent in places such as Haiti where soldier and guns accompany the way infectious disease spreads as a biological expression of oppression, is a perspective that holds significance to people living in the western world, living and dying from long term conditions such as heart failure. I have tried to argue though, that structural violence needs to undergo somewhat of an epistemological transition, and draw on a broader range of methods, in order for such an approach to illustrate how chronic disease can also be a biological expression of oppression. In this thesis I have argued that undertaking a dialogical approach to qualitative research is one way to achieve this. I outlined the Dialogical Integrative Analysis Method as a way to express my own approach to attempting a dialogical approach, and it requires viewing analysis as three aspects; defining data, activating the self/analyst and being in conversation with theory and context. Through using such an approach, I have tried to demonstrate how experience, discourses, utterances

and performances can be explored as mediating the structural violence of living with and dying from heart failure. I have not intended to provide an exhaustive or definitive account of what methods can help illustrate, but rather to show how an enhanced clarity of how we conduct research, on whom, and in relation to what context, may begin to open up some of the 'gaps, slips and sidelines' that Emily Martin (2007) argued are important to avoid perpetuating subjugation in our own work. Other approaches may contribute to that just as well, such as Dorothy E Smith's institutional ethnography (1999), which has a focus on text based practices as reflecting the 'ruling relations' that create oppressive conditions.

Here, in this last section of findings in this thesis, I will offer a brief discussion relating to two of the six people who died during this study and contribute my own reflections on coming to the end of life with heart failure. I have already presented in some length the experiences of some who died, such as Linda, Allan, May and Carol. Here I will conclude by reflecting on Eric and Flora's experiences of living and dying with heart failure as a way to draw on the learning of this thesis and relate it back to the accounts of two individuals as case studies.

7.3.1 Eric

When I met Eric he was really quite poorly. He was mainly confined to his bedroom and had very limited mobility. He had been told by the doctors he could die at any moment. Eric had been living with heart problems for over 20 years. When he was 55 he had his first heart attack. He worked driving heavy trucks, and immediately lost his job and his heavy truck licence, when he was identified as having heart problems. This led to life being financially hard, and when I met Eric, he lived alone in a one bedroom council flat. Eric reflected the broader literature, in that he was at a higher risk of developing heart failure due to his socio-economic status (McAlister et al., 2004), his wellbeing was disadvantaged from the consequences of the deprived community he lived in (McCormack, 2009), and the stressors of both were likely to have negatively impacted his heart (Everson-Rose, 2005).

Eric had been through a range of challenges through his life. He had served and been injured in the military, worked in a hard, low paid physical labouring job, and was still mourning the loss of his much loved wife. After 48 years of marriage, his wife had died, and he missed her still, tremendously. He lived with the impact of both social isolation (Wilkinson & Pickett, 2009) and

low mood (Nabi et al 2010), on his heart.

She was good company you know her patter was good yes she was very nice, but I admit I did take it ill out when she died. I went quiet and people were asking me questions and I didn't want to listen to them you know I would take walks by myself and I would go away in the car on my own and things like that and they always wondered where I was then you know. But what do they say absence makes the heart grow fonder and you miss them you never, ever forget them ever, it will be eleven year. (Eric)

We talked about his wife together and he described how he thought of her each night. As we spoke a photograph of her sat beside him.

Eric: Oh she's here aye she used to sleep on this side of the bed.

RP: Right does that give you a bit of comfort?

Eric: Well it does aye, I fall asleep on my left hand side and I put my arm across.

Eric and I never discussed the words heart failure, but he described knowing he had heart problems and that they were serious problems. It wasn't uncommon in this study, or in the literature that the diagnosis of heart failure wasn't shared (Rogers et al., 2000). He described his heart's condition as not pumping as it should. Eric spent most of his time in bed, and described feeling quite depressed. He was cared for by his two daughters, and he tried to play down being depressed so they wouldn't worry. He felt he was a huge burden on them and wanted them to be able to get on with their lives.

You do get depressed. The girls come up and try and cheer me up and then they go away, I mean they've got their own lives you know, they go away about half past seven or eight o'clock at night and they leave everything ready for me all I need. (Eric)

Eric described putting on a brave face for his daughters, evoking the idea of performing the role of the good patient for those around him. Eric felt that dying would mean his daughters could move on, and even have a better life once his house was sold and they received their inheritance. Eric's performance for me was slightly different, in that it included also a story about key information he had about, what he described as government corruption. I felt like he wanted to show me who he was, beyond patient-hood, and we talked together about his

plans to expose the government.

Eric had heart failure and COPD. He was seeing both a heart failure nurse specialist and a hospice community nurse. They had worked together to build up a relationship with Eric, as despite him having reservations about hospice care, it seemed that his daughters needed extra support in providing care. The relationships around Eric may have reinforced the patient role, and there were obvious pressures put on him to take the care options that were being suggested to him. However the relationships he had with professionals were unique in the context of this research, in that the professionals collaborated together across settings, and this did facilitate access to palliative care that would otherwise not have been available.

After a long negotiation, Eric was admitted for a respite break into hospice. He was not there long but managed to establish a reputation of liking a laugh, and directly contrasting the self management advice given to him by refusing to give up his love of salty crisps. Eric performed the role of the good patient, being brave, humorous and putting on a brave face for others. When I interviewed him at his home, a bag of crisps sat in reach, and we joked about making sure his heart nurse didn't find out about them. Alongside his performance of the good patient, Eric worked the weakness in the norm, displaying his open resistance to the self-management instructions he had been given. However it is quite clear to me that salty crisps were not as significant as Eric's story of hard work, low pay, unemployment, heart break through bereavement and what seemed like a long lingering depression.

About 24 hours into this respite break Eric deteriorated unexpectedly, and died. It was described as a one of the worst deaths they had seen in the hospice, and one where the staff was challenged to control his symptoms of pain, bleeding and seizures. His daughters were with him as he died.

It was fairly unusual for a heart failure patient to receive hospice care, and when I talked with the nurse who had cared for him, she described how she felt less experienced in nursing him in contrast to nursing a patient with cancer. As we talked she explained how even 48 hours before Eric's death they wouldn't have been able to predict he was going to die, and the goal would have been moving him out of hospice. The discourse of unpredictable dying emerged as a justification for excluding heart failure patients from specialist palliative care, and in essence,

Eric had died in hospice more by accident than by design. The hospice nurse explained that heart failure was less predictable in relation to cancer, where they could more reliably nurse a person in the last moments of their life in relation to a more certain timeframe.

Hospice nurse: And often priority, priority then would be a patient that we know for a fact not all the time, but is maybe going to die quite quickly, you know, it would be very obvious they didn't have very long to go and they are having problems with their symptoms so obviously they would possibly get in before a cardiac patient.

RP: Right because they're so unpredictable?

Hospice nurse: Well I think more because the cancer patient is so obvious, have got all of the symptoms and their need is greater at that point.

The discourse around unpredictable dying and symptoms, emerges as a reason not to provide hospice care, yet it is clear that Eric was perhaps quite fortunate that he was in the hospice at the time, even though it was for respite care. The reduction of people to individual patients, symptoms and estimated dates of dying, seems to facilitate a transition from Eric as a person with great needs for specialist palliative care, to a potential cardiac bed blocker, who challenges and disrupts the workflow practices of the hospice. It becomes not the needs of the patient, but the needs of the institution that privileges certain symptoms and better estimated dates of death in relation to hospice access. Here something is wrong with the cardiac patient, not the cancer orientated system. In this sense, the institutional practices, as delivered in this case by the nurses, perpetuates the dynamics of structural violence, as patients with heart failure become excluded from specialist care provision.

Eric's heart failure nurse provided slightly unusual care for him, in that she provided a continuity of collaborative care. She had involved the hospice, but also continued to provide care to Eric and help facilitate the relationship with hospice staff. This relationship highlighted how hospice, with their focus on end of life, in contrast with cardiac services, which are often focused on prolonging life, dealt differently with end of life preferences. The relationships that were developed overcame the usual disjointed care that often happened across different services. The hospice admission required documentation about a not for resuscitation order, and this had highlighted how Eric's resuscitation wishes had never been sought or documented in his admissions in hospital. This illustrates the processes of the medical profession owning

the topic of dying, as argued by Armstrong (1987), with the effect of silencing the patient. The hospice openly owns a conversation about dying, and this revealed how this essential discussion had not been had before, which the heart failure nurse described as usual practice in the hospital setting.

The hospice staff were very keen before all this happened to get a not for resuscitation order because that's another thing that his case highlighted that that's very rarely documented anywhere and it certainly wasn't in our notes because we wouldn't be documenting that anyway but (my supervisor) was asked to do it and it was noted throughout all his case notes that it was very badly documented. (Heart failure nurse)

Having seen this lack of documentation on notes, or even the status of the resuscitation order changed on the notes without consultation with a patient, it was only through the two systems coming together that the way in which medical views dominate over patient preferences, became visible. If Eric had been admitted to a hospital for a cardiac event, it would likely be the medical staff who would have been caring for him, that would have made this important decision, on his behalf.

Eric died of heart failure, and unusually received palliative care services in hospice, care the hospice would have otherwise avoided providing due to the impact on the hospice workflow. He was cared for by kind and caring professionals, who were doing their very best, even if it meant what they focused on was to get him to reduce his salt intake. Eric died badly, but well cared for. I felt Eric worked the weakness of the norm and performed brilliant resistance to the utterances around what causes ill health, by hanging on to his bag of crisps right to his hospice bedside.

The context of Eric's circumstances show he was at increased likelihood of developing heart failure, due to his socioeconomic status and the link between stress and depression with poorer health. In that context, a structural violence was expressed a number of ways in relation to Eric's daily life. His account also illustrated for me the following ways, or even mechanisms, for how structural violence comes to be expressed on an individual level:

- Eric would have been excluded from specialist care ordinarily, and his story illustrates how the institutional practices disadvantage people living with and dying from heart failure.
- The discourses of unpredictable dying, as expressed by the professionals providing care for him, highlight the relaying of disciplinary power (as described earlier in this chapter), where the individual practitioners' belief in the unpredictable dying, regulates access to care.
- The performative aspects of Eric's account show how he conforms and also actively resists the expectations of the good patient. This raises ground for where subjection fails to hold, showing how Eric has alternative priorities, such as being ready to die, and competing explanations for his heart condition, such as the influence of his many life stressors. Eric also performed in our dialogical exchanges as someone who was not defined exclusively as being a patient, but also as a person with powerful knowledge.
- The relationships around Eric served as the conduit between structural violence and individual experience, and this was dynamic, in that at times it served to continue perpetuation of subjugation, and at times provided care that was an exception to the usual rules.

7.3.2 Flora

In my efforts to find patients that were more unwell I asked all of my recruitment sources to help me out. One nurse suggested I recruit Flora to the research study, as an example of a very frail patient that she felt would be happy to talk to me and was very unwell. The ability of the professionals in this study to much more reliably identify patients who were likely to die, when pressed to do so, highlighted the disconnect between the discourse of unpredictable dying, and the ability to estimate the end of life.

Flora reminded me of Linda in that she didn't have close family and was very hard to locate. After following a trail of admissions and discharges I eventually found her in a private residential care home. I met with Flora on just one occasion and interviewed two nurses at the nursing home about her care. Flora was very frail and disorientated. When I met with her she was sitting alone in her single occupancy room with the door open, so she could see out onto the comings and goings along the corridor. Flora was very sleepy and in need of constant

oxygen. She was described by the nursing staff as needing masses of reassurance, which was a challenge to them as they juggled the competing demands of many residents. The staff described being irritated that she left her door open, as it meant she could call out to staff as they passed by. In many ways Flora was fairly new in the home, and may have been either still learning how to perform how she was expected to, or actively resisting the expectations of what it is to be a good patient.

Being a private residential home meant that there was a substantial amount of paperwork required for new residents which included documenting her dying wishes. The nurses talked about the benefits of this facilitating conversation about end of life preference but also described how difficult it would be for them to have these conversations when they didn't yet have a relationship with a resident. Despite being meant to collect this information on admission, staff might delay this and collect it over time. However, in Flora's case her wishes not to be resuscitated had been noted as she had raised this when entering the home. The nurses described however that the usual information they would record would be 'did not discuss' as it felt 'sickening' to ask someone about their wishes when they had just met them.

And we write we've got in hers does not wish to be resuscitated oh it's just that. When we admit someone it's actually an issue we talk about isn't it but when we admit somebody we are supposed to and I don't do it because I think it's a really sickening question because I just don't think it's the right thing to be asking somebody the minute they come in. We have death and dying information and we ask about you know funeral directors, cremation and lots of stuff and if we haven't done that we have to document that we haven't done it and then if we have discussed anything at all because often the GPs don't want to discuss it with them straight away either. (Flora's nurse)

The idea of talking about dying being a gloomy, and indeed sickening task was clear. The professionals illustrate how they determine if, when and how conversations about dying will be undertaken. They indicate the need for an established relationship to be in place before talking about dying, and I wonder if this is because of the need to establish authority in the relationship before having such conversations. Flora felt she was very near dying and described how two nights before my visit, she had felt she was dying, and was alone. She drew on her

sense of faith for comfort and described how she would know in the morning if she was alive or not.

I didn't know if I was dying or what was happening to me because I knew in the morning when I wakened up, would I be here? Would I realise I had died? Understand?
(Flora)

Flora had been recruited after I had pushed for patients that were frailer to be referred into the study, so on some levels it was acknowledged that she was likely to die soon. However the prospect of talking about that with her was not considered an option by the nurses caring for her, even though Flora spoke openly with me about her experiences of feeling in an in between place, where she wasn't sure if she was alive or not.

Flora was waiting for an appointment to see if she was able to get an oxygen condenser, which is a mobile unit that would provide oxygen and relieve her from being physically tied to oxygen cylinders. This physical connection was a source of frustration, leaving her restricted from even visiting the bathroom without assistance. As I talked with the nurses caring for Flora, perhaps asking a series of rather leading questions about the role of the specialist nurses and what sorts of things they might draw on them for, they seemed to slowly realise that the heart failure specialist nurse would be able to facilitate access to an oxygen condenser, something I had seen them do for other patients in their care regularly. They started to look around their office for the phone number for the specialist nurse. As I left I offered the nurse's phone number to them as they hadn't been able to locate it. The idea of ownership of patients underlies the discontinuity of care from one service to another. Flora, now in the setting of the nursing home, was now the responsibility of the home, but it was the heart failure nurse specialist who had access to the mobile oxygen condenser that would have improved her quality of life.

The professionals I met who were involved in Flora's care were all trying to do their best for her, and somehow failed to join up the different aspects of care they offered to ensure she could die with her needs much better met. Flora did not have the key carer relationships that so often navigated the transitions across services. Services themselves default to a sense of ownership of care, and in this case Flora was transferred from one service, the heart failure nurse specialist, onto the private residential care home, who then owned her care. The care

being transferred disrupted the service provision that might have proved very helpful, as the heart failure nurse withdrew care. There were no informal carers able to bridge that transition and ultimately the care home nurses were not even sure how to make any contact back to the heart failure nurse, even though it could have been important. The objectifying of people into patients, makes it easier for institutions to transfer care as if people are commodities, for whom ownership or responsibility can be passed on. This strikes up a discontinuity of care, and one which in this case, left a person immobilised through having much less adequate medical equipment than was actually available to her.

Flora died not long after that visit, never having received a mobile oxygen condenser. The heart failure specialist nurse and the nurses caring for Flora in the residential home were all well intentioned and caring individuals, but somehow a basic but essential difference in Flora's care was not made as the systems weren't able to function together to meet her needs.

I think actually I would just say okay I'll do my job to the best of my ability and hope that one day the system might wake up....Because actually it stinks. (Flora's Care Home Nurse)

The professionals involved in Flora's care were immersed in the idea of not talking about dying with people, which meant avoiding conversations that may have been more difficult for them than the person they were caring for. This unknowing patient was then seen as needing a lot of support and reassurance, when perhaps she wanted their honesty and support with facing dying. Flora was moved around the system in a way that passed on responsibility for her care, to her detriment, and whilst the people involved could identify some of the problems with the systems, they did not see that they had any role or part in addressing those.

My contact with Flora was brief in many ways, and I knew very little about her background. I cannot say how her story relates to the broader dynamics of social inequality, however I think in her case there are still examples of how expressions of structural violence are manifest in individual experience, and I will outline those below.

- Flora's recruitment into the study challenged the discourse of unpredictable dying in relation to heart failure. What was broadly described as very unpredictable, became

more reasonably predictable, once my relationship was established with professionals and I could ask them to really try to better predict dying.

- Flora was an owned object who moved settings, creating a discontinuity in care. The lack of provision of the right equipment for her, despite being potentially available, served to highlight the way in which this transfer of ownership could be absolute.
- The professionals involved in Flora's care were kind and caring, yet the systems approach of transferring ownership and responsibility, led to poor practice, that would not have even been apparent if for not the presence of a researcher.
- Relationships mediate the transfer of knowledge, and the residential home nurses held discussions about dying from Flora, despite the fact she felt herself that she was about to die (which was indeed the case). This reinforces the role of authority and ownership over conversations about dying.
- Ultimately, Flora died essentially attached by a line to her oxygen, when she didn't need to be. The processes of structural violence that serve to fragment patients and care for people with heart failure, kept her from receiving care that could have been easily available to her. This led to a much diminished quality of life in her final days, illustrating how the processes of structural violence can have direct consequences on the very last moments of life itself.

7.4 Summary

In this chapter I have introduced the idea of structural violence and explored the way in which inequalities feature in the social epidemiological literature on coronary heart disease. I went on to illustrate the ways I have explored the processes of structural violence, using methods I have explored throughout this thesis. Dying from heart failure is far from unpredictable, but heavily socially influenced. It may be more challenging than cancer to predict an exact time of death, and that idea of unpredictability is then used in a way, to avoid the issue of dying (both in relation to service provision and conversations with patients). I have argued that coronary heart disease serves as much as a biological expression of oppression as infectious disease does in countries such as Haiti. The idea of unpredictable dying is held onto as a deeply embedded discourse that informs the how and where of people's experience of dying with heart failure. Structural violence is achieved by transforming the knowledge we have about how heart failure is socially influenced in its collective sense, into individual people who are studied as subjects,

perform as patients, become a collection of symptoms, to be managed and organised as objects into, and through, different institutions of care. Dying sooner and faster from a chronic disease if you are poor, is, in my view, the way in which structural violence is expressed in the western world. I have tried to argue throughout this thesis that qualitative research methods that remove people's experience from the context in which they live, and in which we conduct research, can lead to making a contribution to this violence. I have tried to outline how an approach, the Dialogical Integrative Method, may offer various strategies for working with data in ways that can integrate context back into qualitative research methods, and illustrate the social processes through which structural violence comes to be expressed.

8 Discussion

Much of the thinking that led to this thesis originated in my experience of meeting and interviewing Linda, as outlined in the introduction to this thesis. What struck me about Linda were two things, one being the way in which she became fragmented, lost and submerged into the systems of care that were trying to do their best for her, but ultimately may have been implicit in the manner in which she died. The other thing that stayed with me was the way in which I had become as a researcher, a sort of conduit for the relationships and institutions I was embedded in. It challenged me with trying to understand how kind, caring professionals, myself included, participate in poor practices. My experiences with Linda, illustrated how I too was a kind, caring professional who could, inadvertently participate in potentially poor practices, except my practice was research rather than clinical care. In many ways this thesis has involved exploring the processes by which I came to replicate what I had initially been so quick to judge other professionals for doing.

I used my role as a 'researcher', with all the norms evoked by stating such a role: a professional who has knowledge and responsibility to do something useful with the information collected. I was viewed as a trustworthy professional and someone who is different from the interviewee, or research participant. I used my privilege to help facilitate recruitment, learning how to communicate with and convince clinicians to allow me access to their patients. I learned how to blend into the way the institutions work, such as in hospitals, to the point I was one day mistaken for the social worker (as described in Chapter 4, section 4.1). I avoided talking about heart failure, instead talking about the 'heart troubles' and how objective data might speak to aims. Despite my intentions, the work I did was used to advocate general practice as a best model of care for heart failure, even when that wasn't entirely clear. I worked in ways that maintained the sense of disconnect between the accounts people gave and the context of their lives. The work I did will also, perhaps, be used to inform future meta-analyses of qualitative research studies, such as I have critiqued for creating the norms of what it is to be a person with heart failure, which will in turn be used to classify and individualise people. In respect to Linda in particular, I learnt that even in trying to offer support to her carer, I was shaped by the relationships, performances and discourses around me in ways that meant I ended serving the

interests of the institutions I was embedded in. As I described in the introduction, I could have been complicit in the potential for a complaint being discouraged. It remains unclear if the carer would have made a complaint or not regardless of my actions, the point more is that it served as a potent illustration that as a researcher I was embedded in relationships that could influence my actions, despite my intention. This was important for me in terms of developing my understanding of how some of the care practices may be developed and delivered as a reflection of broader institutional settings, and not just a reflection of individual intentions. The potential for a complaint about Linda's death subsided, and I went on to write a thesis for my PhD from her story, along with the stories of the other participants that also lived and died with heart failure.

It is interesting to engage in an analysis of my own practices, even if it also provides a sense on how I participated in a structural violence upon those I researched. It feels unpleasant to confront this, but also very humbling. The point here is, that by reflecting on the discourses, relationships and performances I have engaged in as a researcher, to help illuminate how I think and act in ways that carry many influences, perhaps too we can reflect on how structural violence is perpetuated without getting distracted by judging the individual professionals involved in providing care. This is essential for both exploring new ways to work, but to also recognise the limits to our own sense of agency or autonomy in relation to our roles, be it as a researcher or clinician.

Throughout this work I have focused on two main aims, which were to consider the role of qualitative methods in contributing to how we understand subjectivity and experience in relation to broader social contexts; and to explore the experiences of people living with and dying from heart failure. In this final chapter I will reflect back on those aims, and consider the implications for future work, patient care and the limitations of this work.

8.1 Qualitative Research Methods

Don't study the poor and powerless, because everything you say about them will be used against them. (Bourgois, 2003, page, 18, paraphrasing Nader, 1972).

Research itself can be a tool of structural violence, and qualitative research is no exception to that. Qualitative research, sometimes regarded as a tool to compensate the narrow focused, positivistic quantitative methods, has moved into a new phase. As qualitative research studies grow in use, and sample sizes, we can now look to conduct meta-reviews of bodies of work, and name them as knowledge. However, unlike quantitative work which may explicitly reduce the context of individuals, qualitative approaches can be both poor at clarifying who the work does (and therefore does not) describe, and can disconnect individual accounts from the broader context. Much of this thesis has reflected an exploration into finding a way to systematically work with data that can lead to an analysis which could overcome the disconnect I felt between the way I was describing people's experience with heart failure and the contexts in which those people lived.

I have drawn parallels in this work on heart failure with other settings such as the spread of infectious disease in Haiti (Farmer, 1999, 2004), the role of research in medicalising and objectifying people in apartheid South Africa (Butchart, 1996; Butchart, 1997; Butchart & Seedat, 1990) and the 'othering' of indigenous people, such in New Zealand (Tuhiwai Smith, 1999). In these examples it can be seen more clearly how research can reflect dominant social and political interests. I have argued that Scotland is no exception to this, as illustrated by McCormack's (2009) war without bullets.

Qualitative work is concerned with analysing experience and subjectivity. However, much of the way in which that is done, can also contribute to individualizing accounts in a way that leads to creating a sense of an 'object' of enquiry or object in relation to the way institutions organize and deliver care. In relation to heart failure research, much of the qualitative work is orientated towards thematic analyses of individual accounts, leading to a growing consensus on what it is to live with heart failure that is highly individualistic (Welstand, et al., 2009; Yu, et al., 2008). In this sense the synthesis of qualitative research can lead to the subjugation of

people by individualistic and, as Bakhtin (1981) would describe, monologic descriptions, that reflect dominant medical discourses.

Qualitative methods in relation to social inequalities, or disparities, has emerged as a concern throughout this work. I would argue that all work that relates to health, should consider social inequalities as an integral part of enquiry, given how robust is its association with poor health (Wilkinson & Pickett, 2009), and the evident impact on patient care (Mercer & Watt, 2007; Tudor Hart, 1971). The inverse care law has illustrated how those with the greatest needs, receive the least care (Tudor Hart, 1971), and perhaps reflecting on how we conduct research and contribute to the evidence base that informs practice, can offer insights into how that happens. There is a relationship between research, policy and practice, and when research renders inequalities invisible, that disparity continues through into policies and practices drawn from that work. The issue of poor compliance with self-management practices in the heart failure population, influenced by the disconnect between ill health and the social determinants of health (Leventhal et al., 2005), may be better understood by reviewing the lack of context in the evidence base. Qualitative methods lack careful precision in defining who their populations are, as shown by what is known about samples in the meta reviews conducted, and how methods used can lead to the head and shoulders view of experience, at the expense of the bigger picture.

I outlined the Dialogical Integrative Analysis Method as a proposal to address the decontextualising of qualitative research. Many other approaches address this issue of how qualitative research can lead to decontextualising. The idea of the researcher as bricoleur has been presented (Kincheloe & Berry, 2004; Kincheloe & McLaren, 2002) as a way to overcome the othering of those that are researched (Fine, 1994; Tuhiwai Smith, 1999), or oppressed through the way research contributes to oppressive contexts (Butchart, 1996; Butchart, 1997). Despite these insights, researchers continue to dominate health related research with a very limited range of methods, and mainly methods that draw on thematic analyses of transcripts. It may be time to find new tools to offer health related qualitative researchers that translate those debates into practical processes that researchers can utilize. I have proposed the Dialogical Integrative Analysis Method as a method or process that can guide researchers in the way in which to conduct their analysis.

I have argued that there should be a clear articulation of the relationship between the methods we use in qualitative work and the theories that inform our analysis. The integration of theory and methods, and indeed in some cases theories as methods, creates a self validating relationship between knowledge and theory that leads to monologism, which Bakhtin (1981) describes as the exclusion of perspectives that may challenge dominant world views. In proposing a dialogical approach I am advocating that researchers should make explicit the theories they use and draw on a variety of perspectives and data in order to avoid, or at least limit, such monologic approaches.

There are many tools that can be deployed in a dialogical approach, I have explored discourses (Foucault, 1976, 1977), performative utterances (Butler, 1999, 2005), practices (Smith, 2005), and structural violence (Farmer, 1999) and they all led to similar findings, but all offered unique perspectives on the research aims. The point is not that one theory can provide a comprehensive point of view, but rather the dialogical method proposed integrates the placement of analysis in conversation with theory, to ensure researchers follow more than their own self belief. If researchers take their standpoint alone, by not explicitly reflecting on the theories, or what can be called superaddressees (Bakhtin, 1981) that influence them, then the analysis produced risks offering what Haraway (1988) describes as partial perspective. This partial perspective is at particular risk of an unquestioning replication of the dominant ideologies that surround us, into our work (Haraway, 1988).

I would argue that qualitative research needs to evolve to new levels of rigour to avoid the pitfalls of becoming a tool of structural violence itself. One criterion for improving rigour would be to include a standard of requiring more than transcripts as data, as an important indicator of good quality qualitative work. Further, it should be an essential requirement, in health research at least, to better describe the samples we use, both to protect against misleading generalisations, and to place research in dialogue with broader contextual information. I would also argue for the importance of including a careful examination of relationships between people and perspectives. In this thesis, relationships were the conduit for expressing discourses and performances. Relationships mediate discourses and yet are often controlled by professionals, and exist in hierarchical layers with authority being expressed through them. However, it is not just patients that are influenced by that process, but professionals are also

defined and restricted through discourses and performance. Particular attention to issues of 'ownership' in relationships speaks to the way objectification leads to subjugation.

Qualitative research methods can become complicit in the subjection of people through reflecting highly medicalised views about heart failure, just as psychology used such methods of individualisation in South Africa to support the dominant ideology of apartheid (Butchart, 1996; Butchart, 1997), and medicine claimed the realm of dying itself (Armstrong, 1987). Cathy McCormack (2009) implores us to consider the war without bullets being waged in Scotland, and social epidemiological research (Everson-Rose, 2005; Wilkinson & Pickett, 2009) supports her assertion that poverty, and the gap between rich and poor in Scotland leads to casualties. However, qualitative research in health has failed to integrate such concerns because of its reliance on individualizing approaches. Health related qualitative research can risk becoming the equivalent to the South African researchers (Butchart, 1996; Butchart, 1997), by working in ways that reflect and replicate the dominant social norms that obscure the collective picture of poverty and inequality and how that impacts health. Finding ways to advance a dialogical research method may be one way to challenge qualitative research to rise to the challenge of inequalities in health, and contribute more constructively to doing research that can have relevance, and more importantly has clarity about its limitations, in relation to who it applies to and who it does not apply to.

A particular concern of this thesis was to engage methods that could explicate the processes of structural violence in the context of chronic illness. To achieve this aim a range of approaches were explored, to see if structural violence can make the methodological transition required to overcome the epidemiological transition. The different approaches were selected for their attention to oppression and different perspectives on working with data. The approaches of institutional ethnography (Smith, 1999, 2005) and post-colonial studies (Tuhiwai Smith, 1999) provided a useful underpinning, particularly in relation to the way societal oppression plays out in institutional practices and research methods. Different methods were also chosen because of the different nature of how each interacts with text, with the influence of performative utterances, Foucauldian discourses and the initial thematic analysis, illustrating the many ways in which structural violence can be further explored in chronic illness settings. Institutional ethnography focuses more on the role of social processes, including working practices, and how those pay attention to power (Smith, 2005). Smith (2005) considers the role of experience

and how that provides an entry point into understanding how oppression is expressed in daily life. Butler's (1999, 2000, 2005) work on performativity focuses more on the role of specific language, which shapes how we think and behave. This has some connection with Foucault (1977), who focuses on the role of discourse in engaging power and subjugation. Each perspective offers different ways to explore the idea that broader factors of oppression influence experience, and illustrate that a variety of methods can help achieve exploring the structural violence framework even in the absence of civil wars and infectious disease.

8.2 Dying From Heart Failure

Ryan and Farrelly (2009) posed the question '*if patients with advanced heart failure can be helped to feel better why is it that they continue to suffer?*' (P229), and they propose the answer that it was due to a lack of acceptance by professionals about the incurable nature of heart failure (Ryan & Farrelly, 2009). However I would argue it is about challenging much more than the attitudes of professionals. Throughout this thesis I have tried to illustrate how certain social processes and discourses contribute to how professionals reflect the systems they are embedded in. In many ways, I think an analysis of poor people dying from chronic disease in the industrialised world has been left out of the picture of the development of qualitative health research methods. We have a health industry built on trying to improve health behaviours, but we obscure any broader views of how 'our' behaviour as researchers or practitioners is deeply embedded in social processes around us. Perhaps we become the administrators of the dominant medical view, just as the mine recruitment officers administered the racial selection criteria in South Africa (Butchart, 1997). Dorothy Smith (2005) offers insights into how those discourses become negotiated into institutional practices where those are around the work of being ill, and dying and into the policies, procedures and practices around dying.

This thesis has shown how living with heart failure can indeed be very challenging. Much of the findings in the literature about the difficulties faced by people with heart failure illustrate this, such as variations in health, restrictive symptoms, emotional burden and negative impact on the quality of daily life (Welstand, et al., 2009; Yu, et al., 2008). This growing consensus leads to the formation of assumptions about what it is to live with heart failure and so the subject is formed, and the norms are created about what it is like to be the person with heart failure.

However, what I have argued is that this partial perspective excludes information about living with and dying from heart failure that is essential for obtaining a contextualized and dialogical knowledge, and without this contextualized knowledge, research risks being a manifestation of a structural violence as long term conditions become the biological expressions of oppression in the western world.

The way in which this violence is committed is by using the normative subject to theorize about people with heart failure (Buetow, et al., 2001; May, et al., 2009), which in turn informs how practices develop, based on normative assumptions that exclude social context. When the context that is obscured is one of inequality, in that the poorest people are most likely to get and die faster from heart failure (McAlister et al., 2004), then I would argue that such research contributes to structural violence against those who are most disadvantaged in our communities. This has happened in other contexts, particularly in relation to racial differences (Butchart, 1996; Butchart, 1997; Tuhiwai Smith, 1999), and unchecked, such research becomes a manifestation of dominant perspectives, and in this case dominant biomedical perspectives.

Emily Martin (2007) advised that to avoid subjugation, we must look for the gaps, slips and sidelines where subjugation fails to hold. Representations of the self, as understood and performed, are the first places we need to disrupt our knowledge. These norms, and how people with heart failure live or resist them, are apparent when exploring an analysis of performativity (Butler, 2000, 2005). These perspectives offer insights into the gap between individualistic demands for self-management, and the resistance to compliance with those expectations. The literature reflects these issues of non-compliance (Leventhal et al., 2005), but here I argue that you could consider non-compliance a reasonable resistance against the norms which have been developed in ways that are heavily cultured, gendered and socially classed. Perhaps considering this idea of resistance would offer new perspectives to thinking about ways to support people in living with, and approaching the end of life with heart failure. Indeed such resistance could be akin to Butler's (2000, 2005) idea of working the weakness in the norm. In this thesis, see Chapter 7, I gave the example of Eric's crisp packet sitting in view, just by his shoulder. The way in which it came to symbolise how he could challenge the practices imposed upon him by the professionals charged with his care, shows how aspects of resistance can be performed.

There are also a range of settings, roles and relationships that provide a context for living with heart failure. Those relationships and the way knowledge moves between people helps to illustrate how people live with heart failure in relation to other people, professionals and settings. This can provide further insights into how systems work, and all these perspectives broaden our view to help offer greater insight into daily life, and help disrupt normative assumptions. In this thesis, the way in which knowledge is negotiated and shared through relationships illustrated issues of knowledge and power that exist, with professionals holding knowledge until a patient provides the right cues that they wish to have that information. Professionals outlined to me the dance of knowledge, where they were poised to share information, as soon as there were the right signs that the patient might want to know it. This dance of knowledge happens in a context where professional discourses work to avoid causing distress by withholding information (Tayler & Ogden, 2005). Meanwhile the patient does not know what the professionals know, and so the dance can sometimes lead to information never being shared. It is the professional who will lead that process. Additionally, ownership in relationships illustrates the objectification of people with heart failure. Allan appeared to belong to one geriatrician in particular, and that ownership helped him access better care. However, sometimes people were owned by no one in particular, and could fall through the cracks between one system of care, or institution, and another.

Relationships also formed a key role in mediating performative factors and discourses. They served as non-intentional conduits, where much of what informed interactions were reflections of the way our broader knowledge is formed and were part of the social and medical context in which we are all embedded. However, at times, relationships served a protective function to help avoid this disintegration, which sometimes was provided professionally, and at other times by family carers. I do not mean to overstate the non-intentionality and claim individuals possess no agency, but rather to acknowledge how very well intentioned, caring professionals could engage in practices that could be oppressive, without meaning to do so. I include myself, particularly my conduct as a researcher in relation to Linda, in that group of professionals. Understanding the way we, as researchers, or clinicians, are also embedded in a social context seems important for furthering our understanding of how to re-contextualise those we research on, or provide care for.

Further to the development of the subject of the person with heart failure, and all such associated norms, I have argued that certain discourses function to further objectify people with heart failure. I drew on Foucault (1977) to explore the processes at play here, and suggested that such objectification is a key part of the rationalizing of health care and service provision to people with heart failure, be it access to a specialist nurse, or entitlement to hospice care. However, taking a structural violence perspective raises the question of just who is rationed into, and out of, access to care, and again the literature, both in relation to access to services (McAlister et al., 2004) and social epidemiological data (Everson-Rose, 2005; Wilkinson & Pickett, 2009), shows that such objectifying disadvantages the poorest. The most striking example of this is the focus on the left ventricle dysfunction, and how that is a feature of the research on heart failure interventions (Davis, et al., 2000), yet is also a gendered feature of heart disease (Emslie, 2005). Used as inclusion criteria for services, the left ventricle is part of the heart, and people, or more specifically women, are excluded. By translating people into parts, unpalatable practice, such as excluding women from services, become seemingly reasonable.

Increasingly there is a case to be made to consider people and patients, particularly people living in economically disadvantaged areas, as having many interrelated and complex needs (Mercer, Smith, Wyke, O'Dowd, & Watt, 2009; Peek, 2009), however current discourses serve to dissect people into different symptom and organ systems, which can disintegrate them around institutions of care. This sense of dissection can contribute both to fragmented care, and obscures the broader context of people's social and emotional lives. Linda became a broken hip, failing kidneys, persistent depression, and a weak heart. The part of the system that treated her hip, overlooked her kidneys, but perhaps in predictably complex situations there should be more care to avoid such fragmentation and retain a whole view of the person with many interrelating health concerns.

The social epidemiological data suggests that there is a relationship between the heart broken and the broken hearted, and the data from this research supports the way that social stories about life challenges, strain and challenges do inform people's understanding of their heart failure. Whilst this may be seen not as a priority of those providing care, as indicated by the narrow focus of the self-management literature, the people living with heart failure are backed by substantial research that supports the connections they make between hard lives and

broken hearts. Finding ways to integrate this into care is a challenge, but perhaps one that is worthy. There is a growing interest in primary care in finding ways to address this issue through integrating an assessment and recording of socioeconomic experience in patient care, which may go some way to start addressing this issue (Peek, 2009). Multidisciplinary case management approaches have been shown to be effective (Counsell, Callahan, Tu, Stump, & Arling, 2009) and cost neutral (Counsell, et al., 2009), and may offer some potential for a broader view of people in a more holistic context. It was clear that people living with heart failure had a great level of need in relation to their symptoms, but there were also many social and emotional needs. Finding more room to explore the broad range of needs should be a priority for disease management, in particular, finding ways to include discourses and practices that integrate those needs alongside that of biomedical symptoms.

Finally I focused on the idea of unpredictable dying in this work, as an ultimate consequence of oppressive conditions. It would not have been surprising if any one of the patients in this study had died, particularly given it was a palliative care study focused on people living with end stage heart failure. People living with heart failure themselves had a great deal of insight into the prospect of dying, yet professionals felt they were not able to speak about the end of life due to its unpredictability. I have outlined how discourses around unpredictable dying may facilitate the efficient running of services designed to help care for people at the end of life with malignant diseases, and exclude non-malignant diseases to ensure their continued efficiency. There are factors that increase the predictability of dying, but they are ones that are not relevant to the criteria of institution such as hospices, which are activated by issues such as pain, rather than patients. This reflects the rise of the hospice movement in relation to caring for people dying with cancer, where patients may have an experience of pain that is different that of cardiac patients. However there is some commitment to improve care, so that more people have choices about their care at the end of life (Department of Health, 2008), and how to make this meaningful to people with heart failure will be challenging.

I also propose that unpredictable dying is a performative utterance that protects the authority of professionals, and is possible to maintain due to the ways in which people are subjectified and objectified. Being less predictable than malignant diseases, it appears hard for professionals to acknowledge that they can predict the likelihood of dying less well than for cancers. Rather than risk getting it wrong, a rationale is formed to reduce the need to have

conversations about dying at all, even though people are aware of the increased likelihood of dying. It remains a salient moment to me, that when asked to try harder to find people more likely to die, the professionals involved in this study were more able to find dying predictable after all.

This thesis, and much of the literature in heart failure, focuses on people with advanced heart failure. These findings, however, could have a great deal of application to the condition earlier on in the disease trajectory. Most notably the area of self-management of heart failure is particularly challenging, with issues of non-compliance (Leventhal et al, 2005). Applying these findings and an approach of structural violence to the earlier stages of heart failure might offer insights into how to better align professionally delivered self-management advice, with the daily lived experiences of patients.

8.3 Limitations

There are a number of limitations to this thesis. A key limitation is that I have raised secondary questions in relation to a data set, which had different areas of focus during the data collection. This runs the risk of me replicating, just as I outlined professionals have done in relation to heart failure care, the withholding of information from those I was in contact with about their participation in our interactions. However the questions about context emerged from the data itself, and, as I collected the data myself, it is not a secondary analysis as such. Mostly this thesis has extended the analysis along the lines of questions that emerged through the primary data collection.

I also have run the risk of replicating the same errors as those I have critiqued, by proposing a new method to guide qualitative research. This approach could be just another way in which poor work develops, unless further tested and explored. Whilst I have orientated this method around a dialogical approach, critical reflection of its use in practice needs to be undertaken in order to consider if this provides a useful way forward for qualitative health research. One way in which I have replicated that error is by focusing on the experience of people with heart failure alone, and which also replicates the fragmentation of people into specific diseases groups, even though most people in this study had a range of complicated and interrelated health conditions.

A further limitation of this work is that it runs the risk of critiquing qualitative research to a point where it becomes so dissected, that it becomes hard to see the value in the approach at all. Whilst dealing with subjectivity and experience is very challenging, I hold onto the premise that experience is a worthy and valuable resource for furthering an understanding of people's lives, and that with further work we can sensitise such approaches to integrate more usual levels of context, whilst retaining the value of qualitative endeavour itself.

Finally, I have drawn on different theoretical perspectives that exist in some tension with each other, but perhaps not well explored those tensions. One such tension is the way in which different theories relate to issues of structure versus agency. Mostly I have wanted to maintain a fluid relationship between these rather than committing to one particular account of their interrelationship. This means I have not addressed this debate well, and run the risk of appearing to oversubscribe to either a structure-centred or an agency-centred position at times. I do not mean to imply that people lack agency, however I think analyses that can avoid individualising professionals for the ways in which they may individualise patients, is important for continuing to explore broader social processes. However, neither do I mean to imply that we exist without agency or responsibility for our practices, research or clinic based. A further theoretical challenge is that I have not ventured into exploring in detail how different theoretical traditions define and use concepts such as subjectivity and objectivity. I acknowledge there is some tension in the use of these ideas across positions, however I have not addressed that here.

8.4 Future Implications

More could be done to examine various aspects of illness experience and patient care that I have explored throughout this thesis, including learning further from the inquiry into the meanings of infectious disease in the developing world. Heart failure demonstrates how important it is to conduct health related research in ways that draw on the social epidemiological picture, as whilst heart failure is a disease crucially linked to inequality, this is true of many other health conditions also. There are also links with socioeconomic status and both mental health and chronic conditions. Future work may benefit from a broader, whole

person centred view that can consider multi-morbidity, rather than disease specific approaches.

I think in health research we should start to regard qualitative work more seriously as having the potential to cause harm, particularly in the way in which study findings may be used to contribute to the idea of an evidence base. This need to re-examine the potential of qualitative work to do harm has arisen with a growing body of qualitative work driving a desire to distil consistent findings from a body of work. There is also an over-reliance on singular methods in health related research, for example the vast majority of qualitative research on people with heart failure utilizes thematic analysis of transcripts (Emslie, 2005; Welstand, et al., 2009; Yu, et al., 2008), with some notable exceptions (Sanders & Harrison, 2008; Sanders, et al., 2008). This thesis is a call to the need for exploring new ways to engage in methods of enquiry, not just approaches to research, but actual methods that researchers can engage with and use to guide their practice. I have proposed the Dialogical Integrative Analysis Method to illustrate one way to approach this.

This work has shown that there is a good rationale to redefine rigour in qualitative research, to include more than one type of data, and to preferably include social epidemiological data or other kinds of information that help research to capture the wider context and not just the head and shoulders shot. This rigour should also require a separation, and articulation of, methods from methodologies.

For people with heart failure, my hope is that this thesis has opened up new lines of enquiry that can help us gain a better, more contextualised understanding of what it might be like to be living and dying with heart failure. There are indications that some aspects of care do not function well currently, and the way in which people are individualised and fragmented may well contribute to that. It may be time to move from a model of disease specific medicine, to more whole person approaches, as one way to start to address some of these challenges. One thing that was apparent was that relationships can be conduits for medicalising discourses and performance, but can also serve a protective function against that fragmentation. Such findings may highlight the importance of whole person, relationship based care.

Finally, finding ways to integrate the social narratives of health, illness and dying into what we claim as knowledge about people with heart failure is essential for developing policies and practice that have relevance to those who live with heart failure, and is essential for finding discourses that may speak to broader contexts. A space needs to be made for dialogue about the relationship between broken hearts and the heart broken, to find common ground from which to explore new performances, roles, discourses and relationships in relation to living with and dying from heart failure.

9 References

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10 Appendices

10.1 Appendix A: Interview Schedule

Patient Interview Schedule

First interview: Group 1 patients (in hospital)

Introduction

The researcher will explain that she wants to hear about the patient's experience of the illness, treatment and care, so that care for others can be improved. We particularly want to hear about any problems they have now, or have had recently and about what has helped or would help them. Patients will be encouraged to define their own experiences and perceptions: the following outline is designed to be used by the researcher in a flexible and responsive manner. In particular, the researcher will respect any difficulties patients experience in participating in a lengthy interview due to their illness and will be sensitive to issues such as age, race, gender and culture.

Patient's major current/recent concerns

The story so far: patient's account of illness, treatment and hospital admissions. Main current or recent needs (physical, psychological, social, practical, spiritual, information). How are these needs being addressed and by whom? Ask patient to prioritise these needs.

Contributing factors to hospital admission

What were the key events leading up to hospital admission? How was the decision made for you to be admitted to hospital? Who was involved in that decision? What do you think the purpose of admission is?

Key people and services

Who are the key hospital personnel involved in treatment and care? What do they do to help? Who will provide support and care after discharge from hospital? How do you feel about the help provided in hospital and at home? What do you find most helpful? How could you be helped better?

Physical problems

What symptoms have been/are causing you trouble? Can you tell me about them? If possible, rank the 3 main symptoms.

Psychological/emotional needs

How do you feel in yourself now and generally? Do you ever feel low or depressed? What worries do you have?

Spiritual needs

How do you cope with your illness? What are the things you value most in life? How are these affected by your illness? Have you thought about why this has happened?

Practical and social problems/support

What practical help and support were you receiving before admission? How long for and how did you come to have that service/support? Do you know what support is available and how to get it? Who could you ask for help if you needed more? What kind of family/social support do you get? Do you need more? Have you been given advice and help about finances/applying for benefits?

Understanding of heart failure, treatment and prognosis: Information received and needed

Do you understand what is wrong with you? Can you explain it to me? Who explained it to you and how? Was anything particularly helpful said to you by way of explanation? What treatments/ tests/medication are you having? Do you know what they are for? Do you have any problems with them (side effects, effects on life)? Have you been told what to expect from your condition in the future? Do you have enough information about your illness and treatment? What more might you need? Have you been given information on organisations which could help you or your family? Has the information you have been given helped you (decision-making, reassurance, options, informed choices)?

Communication with professional carers

How do you find talking to doctors, nurses and other professionals? Have you been given the opportunity to ask questions and discuss how you feel in private? Do you think your opinions are taken into account when decisions are made? Who do you think should make decisions about your care?

Communication between patients and relatives

How do you find talking to your carer about how you really feel? Is there someone else you can talk to about how you really feel? Do you think your illness has changed your relationship with your carer, family, friends? Are you worried about your carer?

Communication between professionals

Have you found that the different people involved in your care talk to each other effectively about what they are doing for you? Can you tell me about any times where communication between professionals has been particularly good or bad?

Perceptions of the future

What plans have been made for discharge from hospital and care at home? What services have/will be needed and arranged? What family/social support is available? How do you feel about going home? Are there any concerns about managing at home? What do you expect/hope for the future?

Suggestions for improvements

Have you any suggestions for how things might have been/be done better for you or your family? How could the quality of your life be improved?

Subsequent interviews (4-6 weeks, 4-6 months later)

Subsequent interviews will cover similar ground, but focussing more on care in the community. The interviews will develop in the context of a growing relationship between patient and researcher over time, enhanced by the home setting for the interviews.

Group 2 patient interviews

For patients in Group 2, the interview will be patient-led and paced according to the patient's ability to participate, probably taking place over time rather than as a single interview. We hope to gain information concerning the patient's multidimensional needs and to focus more on palliative care. If the patient is discharged home, a further interview will be sought, as we consider it more likely that the patient will divulge their feelings concerning the end of life in the context of a growing relationship with the researcher and in the home setting.

Carer interviews

Carer interviews will take a similar format to patient interviews, focussing on the carer's own needs and perspectives and how services could be improved, as well as their perspectives concerning the patients needs. The bereavement interviews will discuss issues around death and dying.

10.2 Appendix B: Description of Participants

| Participant | Age | Gender | Depcat | No of Interviews | | | Notes |
|-------------|-----|--------|--------|------------------|-------|-------|---|
| | | | | Patient | Carer | Prof. | |
| Allan | 75 | M | 3 | 2 | 0 | 3 | Allan was referred into the research by his geriatrician. He regularly attended a day hospital where he had a close relationship with a nurse there. He had no family near by and lived alone, but had neighbours and carers in frequent contact. He died in hospital after an admission to control excess fluid. Allan's main health professional was a geriatrician and the day hospital nurse. |
| Linda | 80 | F | 4 | 1 | 1 | 1 | Linda lived alone in sheltered housing. I met Linda at a day hospital, where she was tired and disorientated. She died in hospital after long stay during which she fell and broke her hip. I recorded one interview Linda once but visited her on a number of occasions. Linda did not have a key health professional, but moved around hospitals and wards. |
| Carol | 64 | F | 4 | 2 | 2 | 2 | Carol had very severe heart failure along with a range of other physical health issues. She died in hospital after an emergency admission. She had a close family although relationships were fraught. She was difficult for hospital staff |

| | | | | | | | |
|--------|----|---|---|---|---|---|---|
| | | | | | | | to care for. Her husband was her main carer. Her GP was her main health professional. Carol died during the study. |
| Frank | 85 | M | 5 | 3 | 3 | 3 | Frank was fairly stable but had many other health issues. He lived with his wife. He attended day hospital occasionally and from his notes I learned he also had had early dementia, although this had not disclosed to him or his wife. H received most of his care from his geriatrician. |
| Gloria | 79 | F | 2 | 3 | 3 | 3 | Gloria was widowed and lived alone. She was housebound as her flat was up one flight of stairs and she was unable to walk up and down stairs safely. She had a heart failure nurse, a home help she was close to and a volunteer befriender. |
| May | 78 | F | 5 | 2 | 1 | 2 | May was widowed and had very bad heart failure and painful episodes of angina. She was very articulate and interested in talking about her experience. She lived in sheltered housing where she had been mugged in the past and was afraid. Her carers were her two daughters. May had a heart failure nurse and died in hospice after an extended admission. |
| Ian | 72 | M | 6 | 3 | 3 | 3 | Ian lived with his, and was keen to take part in the research, as was his wife. He died some time after his time in study, informal chat with wife about his death, which was peaceful and at home. |
| Sue | 70 | F | 1 | 3 | 3 | 1 | Sue developed heart failure due to congenital heart problems, and was keen to be involved. Many health problems. Referred to the heart failure nurse service but |

| | | | | | | | |
|-------------|----|---|---|---|---|---|---|
| | | | | | | | never seen. Had told she had six months to live 11 years earlier. GP only key professional involved in her care. |
| Louise | 73 | F | 2 | 3 | 3 | 1 | Louise had a long history of heart problems. She lived with her husband in supported accommodation and her sister and daughter are involved in supporting them. I interviewed Louise three times, her sister once, her husband twice and her heart failure nurse twice. |
| Henry | 86 | M | 6 | 3 | 3 | 2 | Henry lived alone and his wife lived in residential care with advanced dementia. He had fears about dying before his wife as he worried how that would impact her. He had a heart failure nurse. |
| Matthe w | 86 | M | 5 | 3 | 3 | 1 | Matthew lived with his with wife. Has had very interesting sounding surgery recently but seems unclear of HF diagnosis. Recent history of heart problems. GP only professional involved. |
| Helen | 75 | F | 4 | 3 | 3 | 3 | Helen lived alone and had a close community network. She had only just received her Heart Failure diagnosis when I first met her and was devastated. She had a heart failure nurse. |
| Anne | 82 | F | 3 | 3 | 0 | 0 | I met Anne when she was in hospital on an admission. I interviewed her once she returned home. She lived alone and declined carer interviews being done, and had no immediate family. GP declined to be interview. |
| Peter | 81 | M | 3 | 3 | 3 | 2 | Peter lived with his wife and had approximately 30 admissions due to his heart failure until he was given a heart |

| | | | | | | | |
|---------|----|---|---|---|---|---|--|
| | | | | | | | failure nurse. He felt because he is old, some of the doctors and nurses he has come across feel he isn't worth providing care for. |
| Fraser | 81 | M | 5 | 3 | 2 | 1 | Fraser lived alone. His wife died of heart failure, and he was diagnosed with heart failure after collapsing on the day of her funeral. Both had the same heart failure nurse. He was on constant oxygen and house, if not chair, bound. Supportive daughter and son-in-law. |
| Eric | 78 | M | 6 | 1 | 0 | 2 | I met Eric when he was admitted for his heart failure, he was quite unwell and having frequent admissions. When I met him he was bed bound and cared for by his two daughters (who did not wish to be interviewed). He had a heart failure nurse and died in hospice on a respite admission. |
| Maggie | 88 | F | 3 | 2 | 1 | 0 | Maggie lived alone and was recruited via a geriatrician after her first admission to hospital. She had been feeling very low. Her family lived locally and were very involved in her care. She had also just been informed she has diabetes. |
| Flora | 87 | F | 1 | 1 | 0 | 1 | Flora was referred into the study by her heart failure nurse and was extremely frail. She was living in a nursing home and it seemed that she no longer had contact with her heart failure nurse. She was on constant oxygen, and died in the nursing home. She had no immediate family. |
| Stephen | 80 | M | 5 | 2 | 2 | 3 | Stephen was recruited whilst in hospital on an admission. He was very unwell and was described as being end stage. He |

| | | | | | | | |
|-------------------|----|---|---|----|----|----|---|
| | | | | | | | had many complicated health issues over many years. I interviewed Stephen twice, his wife twice and his nurse once. |
| Jack | 73 | M | 3 | 2 | 2 | 2 | Jack lived with his wife; he was very breathless when I met him. He was told that nothing more can be done for him by his cardiologist in front of his 11 year old grandson. He is very worried about dying as he doesn't want his wife to go through that loss. He lost his job due to heart problems. |
| Sub-totals | | | | 48 | 38 | 36 | |

10.3 Appendix C: Consent Form

Patient Identification Number:

CONSENT FORM

Title of Project:

The experiences of people with heart problems and their families:
an interview study

Name of Researcher: Rebekah Pratt

Please initial box

1. I confirm that I have read and understand the information sheet dated
for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time,
without giving any reason, without my medical care or legal rights being affected, or
those of the person I care for. ☐
3. I understand that sections of any of my medical notes may be looked at by a researcher
from the University of Edinburgh. I give permission for these individuals to have access
to my records. (This section does not apply to carers) ☐
4. I agree to take part in the above study. ☐

Name of Participant

Date Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Signature

Date

1 for patient; 1 for researcher; 1 to be kept with hospital notes

10.4 Appendix D: Professionals' Interview Schedule

Key aspects of relevant patient's care

What were the reasons for admission and has the situation been improved/resolved? Prompt for factors or a range of factors across patients, including social as well as physical?

How would you describe this particular patient's condition at the moment? What are their main needs?

What do you think their prognosis is? How do you judge what the prognosis is?

Have you had discussions about condition? Diagnosis? Prognosis? End of life issues? What do you think the patient understands about it? Have you used any written information?

Were there any key factors about this particular patient that guided your decisions about how much information you provide about diagnosis and prognosis?

What support do you feel this person requires in order to maximise their quality of life?
Time permitting prompts– physical, social, emotional? Hospital and community? HF nurse involved at all? Referrals to other services made?

Are current services adequate for meeting this patient's needs?
Time permitting prompts– who should provide it, who does provide it, what would you like to see happen. Does this impact upon your practice?

Could this patient benefit from a palliative care approach? Why/why not?
Time permitting prompts– how would it be of benefit? Would other people also benefit from this, eg family or carers?

General views

Are there any difficulties talking about heart failure with patients and carers? Prompt: are there challenges generally, i.e. do other professionals talk of difficulties? Is the term HF itself problematic?

Is there particular support or training you feel would be helpful to professionals when it comes to discussing end of life issues with patients?

Time permitting prompts– training, support, peer support?

Do you think it is appropriate to have end of life discussions re HF? If so, at what stage is it appropriate?

Time permitting prompts– what are the reasons why or why not to disclose. How do you decide if a patient can participate in this discussion. Would you consult with the carer?

In what circumstances would it not be appropriate to disclose a diagnosis or prognosis to a patient?

Time permitting prompts– what are the aspects of cases like this. Do you have an example you can share with me?

Do you feel that the range of services available for people with HF (hospital and/or community) are generally sufficient, and why? Are there improvements that you would like to see made?

Do you feel that specialist palliative care should play a role in the overall provision of services for people with heart failure?

Time permitting prompts– why/why not, what is their understanding of what this might look like, how might it be different?